FOR ALL PATIENTS TO GET THE CARE THEY DESERVE WITHOUT AN ADVOCATE.

2021 ANNUAL IMPACT REPORT



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Welcome

The American health system is brutally complex. It's expensive. It's confusing. All too often, it offers unequal access to healthcare services and support. And when there are challenges related to food, housing, transportation, work and insurance, getting necessary medical care can seem almost impossible.

At Patient Advocate Foundation (PAF), we have always believed that together we can and must address social and financial barriers that cause or exacerbate inequities in health outcomes. It is with that commitment in mind that we have delivered direct assistance to more than 1.7 million patients since 1996.

Not everyone, everywhere has access to the same things in the same way. This uneven healthcare "playing field" makes safety net services essential. We know that social and financial constraints should not be deciding factors that drive quality of life and survival of disease. We also know that many patients need an advocate to have an equitable chance at attaining quality healthcare. Many patients we help face catastrophic health expenditures that compromise their ability to access care or to provide for basic household needs. And many of these same patients come from disadvantaged communities already burdened by reduced access to care and unaddressed social needs.

In 2021, we continued doing what we do best reaching out, respectfully listening and responding to patients in need while also engaging community partners and healthcare professionals who share our mission. Our diversity extends not just across the variety of patients we serve, but also in our staff and our partnerships.

This report introduces you to both new and longstanding programs. Our problem-solving approaches include collaborations with many local, regional and national non-profit, research and health equity partners. Our case management and financial assistance programs deliver meaningful safety net interventions to break down barriers that often stand between patients and the care they need. Our interactive training and educational products empower patients and build community capacity. Beyond individual service, we are committed to the collection of reliable data and rigorous evaluation that contributes to a national understanding about the impacts of social determinants of health and the value of addressing them through social and financial needs assistance and navigation.

As we look toward the future together, be assured that PAF will continue to deliver responsive patient programming that demonstrates a Passion for Patients, Kindness, Accountability, Respect and Excellence We are deeply grateful for your support of this mission.

Alam J. Balch

Alan J. Balch, PhD Chief Executive Officer





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 2021, and we've helped a cumulative total of more than 1.7 million patients nationwide with support provided by more than 200 staff.

Overall Foundation Impact

Total Patients Served in 2021

Total Patient Cases	153,636
Case Management Cases	20,374
Co-Pay Relief Recipients	60,536
Financial Aid Fund Recipients	59,908
Patient Services Email Helpline Sessions	12,818

Total Patients Served by PAF Between 1996 and 2022

1,710,349

DIAGNOSES SERVED BY PAF



by 37% over 2020 DISTINCT RARE DISEASES

The Programs Through Which We Deliver Direct Assistance

CASE MANAGEMENT



patient assistance programs provide financial support to patients across 132 unique funds

- 16 serve patients living with a diagnosis other than cancer
- 18 serve patients living with cancer
- 16 programs fully administered by PAF for other non-profit organizations

10% MCREASE in case management programs

- 47 disease funds assist with medication costs
- 78 funds provide travel assistance to patients
- 12 funds provide cost-of-living assistance to patients
- 1 fund provides financial assistance to people impacted by COVID-19

What Our Patients Are Saying...

PAF uses a standardized, post-encounter survey instrument across all patient service areas to assess overall patient satisfaction and program impact levels. Each patient directly served by the organization receives a survey and an invitation to share feedback about their experience with PAF. The survey is available in English and Spanish, and can be completed online or in hard copy via mail. The 2021 combined survey **completion rate was** 5% with high rates of satisfaction across all patient programming. Respondents reported an **overall** satisfaction rate of nearly 9.

2021 Overall Patient Satisfaction Rating 9 of 10

Patient Ratings for PAF Service

4.6 of 5 knowledge & professionalism of staff

93% 94% indicated that PAF

provided valuable help

would recommend PAF to others

% of Respondents That Would Recommend **PAF to Others by Program**

Co-Pa

Relief



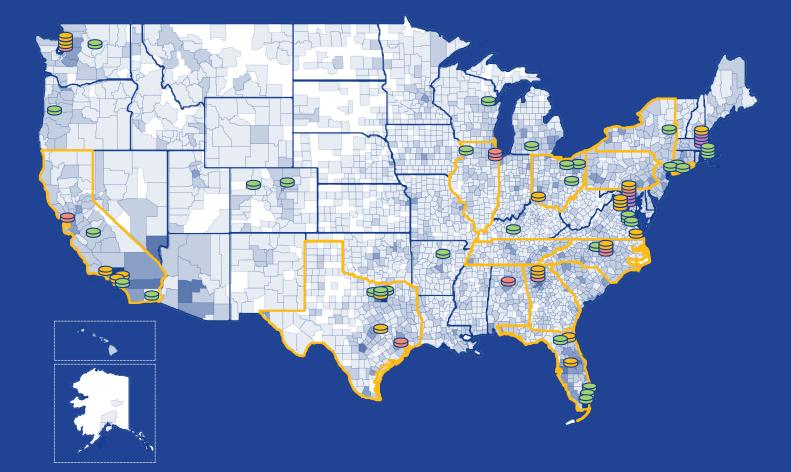


Financial Aid Funds

Service to All 50 States

PAF served patients in all 50 states and Washington D.C. in 2021. Using county-based data, the map below represents the locations of patients we served and provides insight into our national reach and engagement activities. The map depicts the number of PAF patients served by county while each chip represents a specific PAF engagement location.

The COVID-19 pandemic continues to impact conference and event participation, with the majority of events transitioned to interactive, virtual formats. While we missed face-to-face interaction, the virtual framework expanded PAF's reach and collaborations, providing access to larger, new, diverse and/or non-traditional audiences.



PAF Population Hotspot Indicators

- Less than 10
- 11-100 Patients
- 101-500 Patients
- 501-1,000 Patients
- □ > 1,001 Patients

PAF National Impact

- Research Dissemination Through Conferences
- Academic Research, Evaluation & Patient Experience Partners
- Case Management Non-Profit Program Partners
- Scholarship for Survivors Awardees

PAF Top 10 Patient Service States

Florida: 15%	North Carolina: 4%
Texas: 11%	Ohio: 4%
Georgia: 7%	Pennsylvania: 3%
California: 7%	Illinois: 3%
New York: 5%	Tennessee: 3%

COVID-19 Response

As the COVID-19 pandemic continued to impact our nation in 2021, PAF remained resolute in our commitment to directly assist and educate patients and families affected by this illness. We increased our understanding of COVID-19's impact on the individuals we serve through survey initiatives, including our COVID Longitudinal Survey Series. We also evolved our workforce strategy in accordance with shifting workplace guidelines and recommendations, placing an emphasis on the preservation of our staff's health and safety and our ability to deliver uninterrupted, high-quality services to our patients.

"I was diagnosed with COVID, spent 13 days in the hospital, and 14 days in quarantine. As I was recovering my bills were still coming on top of medical bills. I contacted PAF and was connected with a case manager, she provided the most professional patient care service a person can give. She was very knowledgeable and helpful and made sure that she helped with every grant I could qualify for. Thank you so very much PAF."

– Lisa

In 2021, PAF assisted COVID-19 patients through multiple programs and resources including:

- COVID Care Resource Center
 patientadvocate.org/covidcare/
 - COVID Care Webinar Series
 - COVID Care Resource Directory
- **COVID Care**, case management support program patientadvocate.org/covidcare/help/

EXPANDED

Co-Pay Relief

to include critical coverage for **medical insurance**

premiums

TANCE

 PAF's Co-Pay Relief COVID-19 Fund copays.org/funds/covid-19/

Our **COVID Care Resource Center** continues to provide patients, families and healthcare professionals with critical information and resources

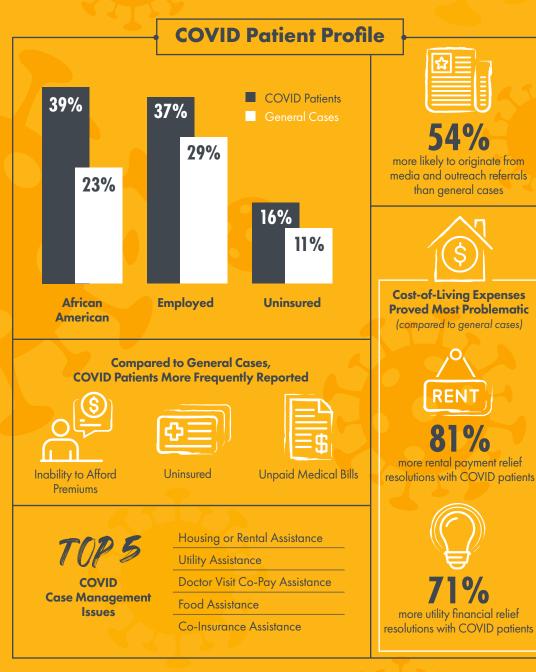
specifically related to COVID-19. The Center houses more than 440 educational resources and experienced an 85% increase in total views in 2021. In addition to publications, the COVID Resource Center offers an on-demand webinar series featuring speakers discussing topics that include:

- Coronavirus 101: Learn from PAF's Epidemiologist
- Three Good Ways to Plan for Your COVID-19 Care Right Now
- At a Loss? Your PAF Toolkit for Dealing With Work Disruption, Decreased Income, and Paying for Living Expenses During the COVID-19 Pandemic

patientadvocate.org/covidcare/

2021 COVID Case Management Service by the Numbers

Case management interventions that uncover and respond to healthcare barriers provide the core inspirational values for all PAF services. We bring our case management experience to bear in support of those diagnosed with COVID-19, documenting their demographics, issues and resolutions. While we see many similarities between the general PAF patient population and those specifically impacted by COVID-19, we did see some differences, including a higher percentage of patients who were African American, employed and uninsured. **PAF reached more than 3,000 patients through our COVID-19 assistance programs and provided COVID-specific educational content that received more than 18,000 views.**



PAF's COVID Longitudinal Survey

Series collected information about the pandemic's impact on patients' lives.

Building on responses from a 2020 baseline cohort of approximately 4,000 patients, the final survey in this three-part series captured data points from 1,400 of the original participants in summer of 2021.

For more on this survey project and COVID survey publications, visit: tiny.cc/datacorner

COVID- 19 Survey: Nonmedical Assistance & Need

> needed help paying for food

> > 54% needed help with utilities

31% needed help paying for internet, data or phone

65% wanted support for their emotional health

Additional COVID-19 Survey data highlights are located throughout this report.

Case Management

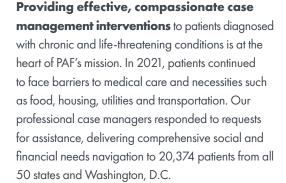
New Case Management Programs:

Esophageal Cancer CareLine

Cincinnati Financial Navigation Program

PanCAN Financial Navigation Program

Rare Disease CareLine



One-on-one case management support that navigates patients to safety net programs is particularly important for populations that experience social needs gaps associated with the social determinants of health. These include disabled patients, rural, low literacy, limited resource patients, older patients and racial and ethnic minorities. A primary focus of our interventions is the mitigation of negative effects that out-of-pocket healthcare and unaffordable cost-of-living expenses have on patients and their families. Case managers work directly to resolve access issues while modeling strategies for negotiating resolutions to medical debt. They also educate individuals not only on options for healthcare coverage and relevant resources, but also in skilled communications with their providers. In 2021, these efforts resulted in **\$23,039,920 in debt relief secured on behalf of patients**.

Of the 34 case management programs in 2021, 4 were new programs and 16 programs were administered by PAF for other non-profit organizations. These highly valued collaborations bring together organizational strengths, expanding the reach and scope of impactful interventions for patients in need.

increase in patients 75 and older 26% of case management patients report being retired **46%** of case management patients earn less than \$24,000





A Message from Amy What PAF does for patients like me with a rare disease



tiny.cc/pafamy

RARE DISEASE CARELINE

PAF further expanded services to special populations in 2021 with the launch of the Rare Disease CareLine. Data shows that when compared with the general case management population served by PAF, patients diagnosed with a rare disease are more likely to:

- Identify as disabled or retired
- Earn an annual income below \$24,000
- Report having health insurance coverage (91%)
- Be insured by Medicare or Medicaid

Individuals suffering with a rare disease are often impacted by issues uncommon to other disease populations, including difficulty obtaining a diagnosis, lack of access to specialized care and/or providers that treat their condition, and higher out-of-pocket expenses for out-of-network services, providers and off-formulary or top-tier medications.

raredisease.pafcareline.org

Financial Services



CO-PAY RELIEF

PAF recognizes that many patients cannot adhere to prescribed medical care without financial help. The Co-Pay Relief (CPR) program helps reduce the financial distress eligible, low-income patients experience when faced with various costs by providing direct financial assistance with co-payments, co-insurance and deductibles for medications prescribed to treat and manage their disease. Launched in 2004, CPR operates in compliance with the guidance provided by the Office of Inspector General (OIG) while delivering best-in-class service with an emphasis on patient-friendly and high-quality service.

More than **60,000 patients were approved** for CPR help in 2021 through a total of 39 open disease funds, with **grant payments totaling \$240,511,901**. CPR **expanded assistance to include critical coverage for medical insurance premiums** in 30 disease funds in 2021.

FINANCIAL ASSISTANCE FUNDS

PAF's Financial Assistance Funds award small grants to eligible low-income patients for non-medical expenses including transportation, food, housing, short-term lodging and utilities. The economic impact of COVID-19 continues to threaten financial stability of US households, compromising access to necessities and making the safety net support offered by these programs more critical than ever. Our financial call counselors handled 243,783 incoming calls in 2021.



al assistance hed in 2021



PAF also partners with other non-profit organizations to manage the administration of their financial assistance programs. In 2021, PAF's financial aid specialists delivered assistance to 59,908 patients and distributed a total of \$132,500,417 to patients in need, a 12% increase over 2020.



A Message from Janice PAF's Co-Pay Relief program was a godsend



tiny.cc/pafjanice

PATIENT IMPACT: EDIE'S STORY

Edie Lymphoma

"From the moment I first spoke with my case manager a lot of the stress I was feeling to help my brother find financial support for his cancer treatment began to subside. She explained to me that there were so many programs available to people like my brother that were horribly affected by the pandemic and then found themselves with a cancer diagnosis. She helped me apply for financial aid for my brother at his Cancer Center, which he qualified for, and in less than 5 working days he was approved for 100% financial aid. Today he had his first meeting with his oncologist and tomorrow he has his first biopsy. He is on track to begin lifesaving chemotherapy in the next 5 days. He is a vibrant person that now has a great shot at remission from his suspected Lymphoma. In our family, we are eternally grateful for the knowledge and the "can do" spirit shown us by the Patient Advocate Foundation."

- Edie's Sister

APPLICABLE RESOURCES & PROGRAMS:

As COVID-19 continued to impact our nation in 2021, vulnerable patients and those facing a new diagnosis needed expert and expeditious help to overcome the additional health and financial impacts created by the pandemic. PAF directly assisted patients and families impacted by COVID through multiple programs and resources including:

COVID Care Resource Center

• PAF's Co-Pay Relief COVID-19 Fund copays.org/funds/covid-19/

- **COVID Care** case management provides patients and caregivers with services that are responsive to their needs, including but not limited to:
 - Eligibility and enrollment into Medicare, Medicaid, disability,
 ACA plans/insurance, facility-based charity care and financial aid programs
 - Negotiation of payment plans or discounts for medical care

patientadvocate.org/covidcare/help/





Healthcare Impact

PAF's COVID-19 Longitudinal Survey Series collected information about the pandemic's impact on patients' lives.

43% reported they had trouble

reported they had troubl covering healthcare expenses before and during pandemic

• 17% reported that pandemic-

reported that pandemicrelated employment change impacted health insurance coverage

<mark>@</mark>77%

reported health insurance impacts stopped or delayed medical care

15%

reported taking on unpaid caregiver role during the COVID-19 pandemic

2021 Case Management Data

\$24M⁴ in documented debt relief obtained through case management interventions

11% of general case management patients were uninsured

16% of COVID case management patients were UNINSURED

Patient Education & Communications

educational resources earned national award recognition in 2021

having problems getting a claim paid." PAF's award-winning and ever-expanding education initiatives provide actionable advice and guidance to patients, caregivers and healthcare professionals, with a range of topics in a variety of formats. Educational products are free to the public and available on demand. The ongoing development of interactive trainings to deliver comprehensive education through a series of modules aimed at caregivers and navigators as well as various organizations, has advanced PAF's reach far beyond those who receive one-on-one service through our case management professionals.

The Education Resource Library (ERL) houses PAF's full catalogue of educational content, with 44 new or updated content pieces added in 2021. New filter options streamline user interactions and create easily identifiable categories, including: Medication affordability, Disability, Insurance eligibility & enrollment.

patientadvocate.org/explore-our-resources/education-resource-library/

Top Utilized ERL Resources

The National Financial Resource

Directory is PAF's most utilized resource and provides users with a customized list of relevant resources.





Engaging with Insurers: Appealing a Denial Engaging with Insurers: Appealing a Denial received a Digital Health Award in the Publications Booklet/ Brochure Category bit.ly/3vdjCne

Top Interactive Trainings

Health Insurance Denials & Appeals Training Series: Don't Take No for An Answer received a Digital Health bronze medal award in the Media/Publications Video Series category. This nine-module interactive training takes participants through the process of identifying, understanding and addressing a health insurance denial.

846 nodules completed in 6 months

53% reported an increase in knowledge

59 series graduates 155K/year healthcare consumers reached by graduates

Disability Training Series and Complimentary Guidebook *bit.ly/3iahNUx*

COVID Webinar Series tiny.cc/covid-webinar-series

This year, a focus on increased virtual outreach and engagement raised education department posts on Facebook by **124%**



Migraine Matters, an online educational resource tool for patients with migraine and headache diseases, was established through partnerships with the Headache and Migraine Policy Forum and Coalition of Headache and Migraine Patients. The goal is to expand awareness and utility of the tool, which had more than 22,000 unique visitors in 2021. migraine.pafcareline.org

Matters of the Heart Working together for health...because it matters

shared the voices

of patients and staff while

our online communities.

Matters of the Heart (MOH), is a self-directed online education tool providing tips and resources on heart disease prevention, heart-healthy lifestyle and managing insurance or financial challenges. Featuring articles, videos, webinars, a cardiovascular resource directory and guided chatbot, MOH had 5,212 unique visitors and 11,000 page visits in 2021. patientadvocate.org/matters-of-the-heart



Written/E-Mail Communication

427,786 (126,774 opens)

240% total subscriber growth

Video Communication

118%

increase in video content engagement over past 6 months

37,443 views in 2021







helps with medication costs



SUBSCRIBER ENGAGEMENT & GROWTH

Corporate communication activities increase awareness and utilization of PAF programs and educational resources, expanding the reach of our services to patients, caregivers, healthcare professionals, community-based partners and others. The development of timely, multichannel communications focused on engaging content and dissemination methods that respond to both traditional and emerging audience preference is key. In 2021, we increased self-directed video production efforts, and

Top 10 Public Communications by Viewership

- Navigating the Disability Process: An All-new PAF Training Series and Guidebook bit.ly/3iahNUx
- Patient Advocate Foundation Announces the Launch of the Rare Disease CareLine
- Paula's Story: Case Management Interventions **Reduce Emotional Distress** vimeo.com/572629236/cb448b68ff
- Podcast: Pharmacists Help Address Social Determinants of Health tiny.cc/pafsocialdeterminants
- Discussing Out-of-Pocket Medical Expenses
- PAF's Co-Pay Relief Expands Assistance to Cover Insurance Premiums Through HIV, AIDS and Prevention, Cystic Fibrosis and COVID-19 Funds

 We Have Direct Financial Assistance Available for Patients With COVID-19 copays.org

building more personal, authentic relationships with

PAF researched, developed and distributed extensive

written, video and audio communications to online

sharing more than 100 public communications and

experiencing a 240% total subscriber growth in 2021.

subscribers based on their chosen topic areas,

- Health Insurance Denials: Don't Take No for an Answer
- SSA Launches New Website for People Helping Others
- Need Help With Medication Costs? Pervez discusses how PAF helped him

of patients indicated the best way PAF could help them during the 40% PAF could help them during me COVID-19 pandemic was paying for medical care and medications 2021 Longitudinal COVID Survey

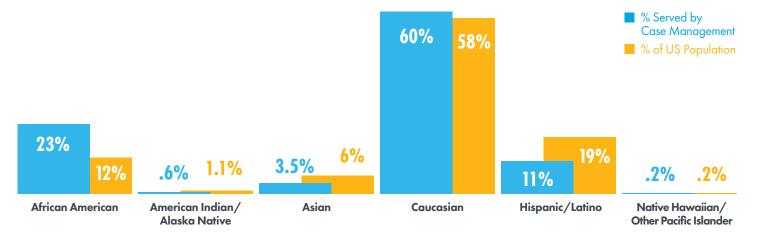
Health Equity & Community Engagement

3,600+ individuals connected to PAF through virtual outreach

47% of case management patients earn less than \$24k annually PAF's commitment to addressing health equity continues to be a guiding philosophy that informs program design, planning and implementation across the organization. The primary purpose of these activities is to amplify the need for shared efforts that address the social determinants of health that continue to exacerbate inequities.

The COVID-19 pandemic only intensified the need to initiate and elevate health equity activities across the entire health ecosystem. The virtual environment necessitated by the pandemic allowed us to reach not only **3,650 individuals across the country,** but also to engage with:

- Providers in the cancer community to develop strategies to prioritize cancer equity
- Researchers to explore opportunities to expand engagement of racial and ethnically diverse populations in clinical trials
- Fellow advocates to integrate the need for an equity-centered approach to support persons living with rare diseases



PAF's Progress in Serving Patients That Reflect the Diversity of the US Population

PAF's Health Equity Affinity Group (HEAG),

is comprised of PAF staff dedicated to bringing their lived experience to help inform internal business operations and guiding strategies for external community outreach and engagement. PAF's staff is a microcosm of the patient populations that we serve, and many have experienced first-hand the unaddressed social needs gaps caused by social determinants of health. The insights provided by the HEAG improve our ability to apply key health equity principles to PAF program design, implementation and communication strategies. Selected for participation in the inaugural **Robert Wood Johnson Foundation Equity Learning Lab**, launched in March 2021, PAF's HEAG has developed a strategic plan to guide and evaluate progress in certain areas over the next three years including:



SELFMADE HEALTH NETWORK

PAF administers the SelfMade Health Network (SMHN), one of eight national networks supported by the Centers for Disease Control and Prevention (CDC) to advance the prevention of tobacco use and cancer in populations experiencing tobacco- and cancer-related health disparities. SMHN implements evidenced-based strategies, including training and technical assistance, to address cancerand tobacco-related disparities among populations with low socio-economic characteristics. Webinars are used for training, reaching diverse audiences and geographies in **more than 30 states**. 2021 topics included:

- Exploring the Opportunities to Reduce Risks Along the Cancer Control Continuum tiny.cc/reducecancerrisk
- Men's Health: The Intersection of Cancer Survivorship, Health Equity, Socioeconomic Factors tiny.cc/pafmenshealth

SMHN staff provided hands-on technical assistance support – 9 HOURS to National Comprehensive Cancer Programs 30 HOURS to National State Tobacco Control Programs

SMHN aligned efforts with two fellow national networks to launch the **Tri-Networks HPV Learning Collaborative**. This Collaborative provides hands-on technical assistance to State Comprehensive Cancer Control Programs to implement evidence-based strategies to increase

Memphis Black Breast Cancer Screening

Initiative links Black women to mammography screening. PAF's SMHN and the Memphis Breast Cancer Coalition have collaborated for the past three years to increase mammography screening among Black women living in Memphis zip codes with high risk and breast cancer mortality rates. The annual goal is to screen a minimum of 25 women. More than twicethat number (53 women) received mammography screening in 2021.

Participants were reached through 4 face-to-face outreach events (with social distancing protocols in effect) held in partnership with a federally qualified health center in 3 Christ Community Health Center

> **21%** of case management patients report a breast cancer diagnosis

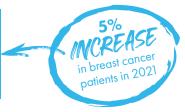
Human Papillomavirus (HPV) vaccination to prevent cervical cancer. This project was selected and **published by the CDC as a success story**: National Networks Come Together to Help Prevent HPV-Related Cancers.

https://www.cdc.gov/cancer/ncccp/successstories/national-networks.htm

locations. Uninsured or underinsured women were connected to the Breast and Cervical Cancer Screening Program and received information about topics including:

- Breast health and the importance of yearly mammography screening
- Local resources and eligibility for transportation, screening and other health support, including those available through the CDC and PAF

Participants also received a COVID-19 home cleaning kit and other protective equipment provided by local partners.





"We wanted to create a model that works through this Collaborative to show that communities can prevent cancer more successfully when they have the right partners, plans and solutions. We will share our learnings from this project with CDC, which can help guide states on HPV interventions in the future."

Shonta Chambers, MSW

Principal investigator for the SelfMade Health Network

PAF's Shonta Chambers served as co-chair of the Elevating Cancer Equity Working Group, a collaboration of the National Comprehensive Cancer Network, the National Minority Quality Forum and the American Cancer Society to help healthcare providers and policymakers work toward equitable cancer care. tiny.cc/paffightcancer PATIENT IMPACT: ROMELIA'S STORY

Romelia Breast Cancer

"Thank you for approving my grant. I currently have stage 4 metastatic breast cancer. I was diagnosed with stage 2 five years ago, received intravenous chemotherapy, surgery and radiation. I lost all my hair, developed severe neuropathy in my hands and feet and felt horrible. Three years later I was diagnosed with stage 4 ... I then lost my job. This funding will help me with travel, food and housing. Nutritious food is what I need, and it is more expensive. It will also help with gas. I have to travel two and a half hours to my doctors and rent a motel if the appointments are early. Thank you so much, you are much appreciated."

- Romelia

APPLICABLE RESOURCES & PROGRAMS:

PAF's **Financial Assistance Funds (FAF)** award small grants to eligible low-income patients for non-medical expenses including transportation, food, housing, short-term lodging and utilities.

243,783 incoming FAF calls processed



The DONNA Foundation partnered with PAF to offer the **DONNA CareLine**, providing free and confidential navigational assistance with financial and practical challenges that impact access to healthcare. donna.pafcareline.org/





Employment Impact

PAF's COVID-19 Longitudinal Survey Series collected information about the pandemic's impact on patients' lives.

73%

of employed respondents experienced work disruption due to the COVID-19 pandemic

90% reported changes

in employment during the pandemic that reduced their income

58%

of employed respondents were NOT able to work remotely during the pandemic

67% reported they stopped/ delayed medical care due to losses in workrelated income

2021 Case Management Data

21% of case management patients report a breast cancer diagnosis

report Financial Cost of Living issues

2021 Case Management Service by the Numbers

20,374 TOTAL CASE COUNT

317,089 TOTAL CASE MANAGEMENT CONTACTS

AVERAGE CONTACTS PER CASE

HOW PATIENTS FIND PAF CASE MANAGEMENT SERVICES





Government Agency or Representative



Healthcare Organization or Representative



Media and Outreach



Patient previously served by PAF



Professional Organizations

- 64% INCREASE in referrals from healthcare organizations or representatives

THNICITY	INCOME	EMPLOYMENT
23% African American	46% < \$23,999	21% Disabled
1% American Indian/Alaska Native	30% \$24,000 - \$47,999	29% Employed
4% Asian	12% \$48,000 - \$71,999	2% Full-time Student
2% Blended Race	5% \$72,000 - \$95,999	1% Homemaker
60% Caucasian	3% \$96,000 - \$119,999	26% Retired
11% Hispanic/Latino	4% \$120,000 or More	3% Self-employed
.2% Native Hawaiian/Other Pacific Islander	AGE	18% Unemployed
NSURANCE STATUS	2% Birth to 18	10% INCREASE
89% Insured	17% 19 to 35	in the retired category
11% Uninsured –	31% 36 to 55	Cuina
	42% 56 to 75	and the second second
	8% Over 75	

-11% ///CREASE in patients over 75

CASE MANAGEMENT STAFF





of case managers have been with PAF for more than 5 years

of case managers speak Spanish

Hispanic/ Latino

African American

2 or More Races

Caucasian

TOP WAYS PAF CASE MANAGERS HELPED PATIENTS

Obtained utility financial relief
Located rental payment relief
Facilitated assistance with out-of-pocket medical costs
Educated on disability eligibility and enrollment
Educated on health insurance eligibility and enrollment
Negotiated discount on out-of-pocket medical costs
Negotiated payment plan for medical bills

TOP 10 DIAGNOSIS CATEGORIES SERVED BY CASE MANAGEMENT



Chronic or Debilitating Conditions



Diseases



Diabetes

Nervous System Conditions

Pulmonary

Conditions

Cardiovascular

Infectious

Disease

Conditions



Vascular

Gastrointestinal & Hepatology Diseases

disease funds assisted patients with insurance premiums in 2021

Patients eligible for support through these disease funds could use the grant award to cover both medical insurance premiums and prescription medication copayments





Average Contacts per Approved Applicant









PATIENT IMPACT: KAREN'S STORY

Karen Colorectal Cancer

"My case manager was a tremendous help to me and my family! As a two-time cancer patient, life can get really tough, physically, mentally and financially. When she called me, I was in a funk and was crying my eyes out. She spoke to me in a way that made the warrior inside me stand up! I was able to gather myself and tell her my problem, and she went to work right away! She was able to help me change my insurance so that I can afford the monthly premiums. I never knew I could do that. If she had not suggested it, I would still be trying to pay almost \$200 a month, or having my policy canceled, because I couldn't. I also would not have the pleasure of paying \$1 a month for my new insurance premium that covers all my doctors and hospital needs ... I am grateful for the day she called me; I will never forget her. PAF has truly been a blessing to me!"

- Karen

APPLICABLE RESOURCES & PROGRAMS:

Our **Education Resource Library** houses an extensive catalogue of PAF educational content, with a dedicated section for insurance eligibility and enrollment that contains actionable material focused on plan evaluation and selection including:

- Step-by-Step Guide for Choosing a Health Plan
- Identifying the Right Policy Among a Sea of Plan Options

• 10 Tips to Help You Get the Most Out of Your Health Insurance: An Interactive Training bit.ly/3jC2zqn

Living with colorectal cancer can be overwhelming, causing extreme stress for patients and families. The **Colorectal CareLine** provides free and confidential navigational assistance for financial and practical issues that create barriers to treatment and recovery. *Call* 866-657-8634 for assistance.





Financial Hardship

PAF's COVID-19 Longitudinal Survey Series collected information about the pandemic's impact on patients' lives.

75%

of respondents experienced financial hardship during the pandemic

45% reported their financial situation deteriorated during the pandemic

65% had trouble covering

medical and nonmedical costs

66% sought financial assistance from a safety net program

2021 Case Management Data

18% increase in psychosocial support issues

43% of case management patients

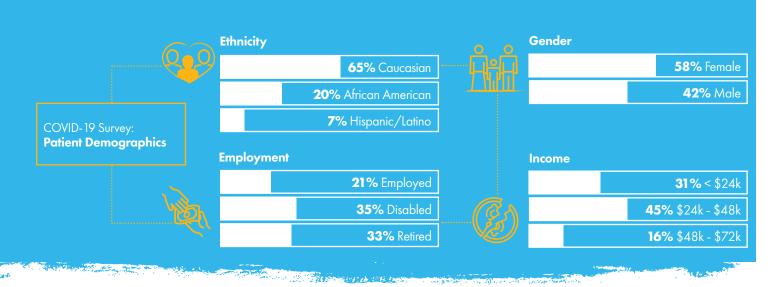
11 % of case resolutions involved health insurance eligibility and enrollment

m

Health Services Research, Patient Experience & Evaluation

In 2021, PAF continued its momentum to systematically highlight and amplify the patient voice across all research and evaluation activities. We used multiple channels to share the rich and varied experiences of the patients we serve, with feedback achieved through the COVID Longitudinal Survey Series, Patient-Centered Outcomes Research Institute (PCORI) patient engagement awards and launch of the Patient Institute.

The COVID Longitudinal Survey Series collected information about the pandemic's impact on patients' lives. Building on responses from a 2020 baseline cohort of approximately 4,000 patients, the final survey in this three-part series captured data points from 1,400 of those original participants in summer of 2021. patientadvocate.org/explore-our-resources/research-evaluation-data-corner



Featured Future Work: Academic Partnerships to Explore Vaccine Acceptance

Vaccine hesitancy was a growing challenge for public health even before the onset of COVID-19. To explore patient perceptions around vaccines, PAF partnered with research teams at the University of North Carolina Chapel Hill and the University of Alabama at Birmingham to conduct in-depth analyses of the data collected through our COVID Longitudinal Survey series. Journal publication is anticipated in 2022.

Preliminary results of the UAB collaboration were shared at the ASCO Quality of Care Symposium: ascopubs.org/doi/abs/10.1200/JCO.2020.39.28_suppl.148



of respondents were unsure about receiving a COVID-19 vaccine in December 2020

indicated that they had trouble locating a place for COVID-19 vaccination as of July 31, 2021



reported being fully vaccinated against COVID-19 as of July 2021

of unvaccinated respondents cited safety concerns as the reason for vaccination delay

PAF'S PCORI PATIENT ENGAGEMENT AWARDS

Paving a Pathway to Engage Underserved Populations in Research

2 Co-Learning & Collaboration Around COVID-19: Connecting Researchers and Underserved Patients

3 Addressing Determinants of Health Together: Pharmacists and Patients Co-Designing PCOR Priorities

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Our first Patient Insight Network survey, focused on patient engagement in research and included 3,000 respondents from diverse communities across every state of the US. Initial results indicate the following:

- patients want to be meaningfully involved in research development
- patients want to be informed about results and findings
- patients feel that researchers need a better understanding of the challenges low-income, uninsured and/or minority patients face

Patient Engagement in Research Survey: Paving a Pathway

39% would participate in fresearch if contacted

43% feel they have valuable experiences to share

would join a research team if tech training provided 97% believe the patient voice and perspective is important in research

52% say they HAVE the tech skills required to participate

The **Co-Learning & Collaboration Around COVID-19: Connecting Researchers and Patients** project builds a learning community of patients, caregivers and researchers by connecting these stakeholders

in person-centered, interactive workshops that provide communication skills and team building training. The goal is to facilitate co-learning, including opportunities for real-time networking and matchmaking between research teams/projects and potential patient advisors, and train a cohort of patients, readying them to engage specifically around COVID-19-related topics and projects.



Our newly launched Patient Insight Institute focuses on ensuring that healthcare is informed by the whole patient experience by generating evidence, building capacity and expanding the engagement of those who have been historically under-represented. The Institute builds on PAF's rich 26-year history of direct services and data collection to strategically understand and amplify patients' and caregivers' experiences of how social determinants of health and social needs navigation impacts health outcomes. Our outreach and network building helps researchers, policy makers, industry and health professionals effectively engage limited resourced populations.

How We Shared Our Work



31% Journal Publications



Through leveraging our research, evaluation and engagement partnerships, we grew our network





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Patient Congress

Patient Congress 2021 featured Health Needs Navigation research, policy and advocacy skills sessions introducing financial and social needs navigation as a practical and proven health equity approach for improving patient experiences and outcomes. The event, held in October, featured sessions focused on:

- Needs navigation to reduce stress for patients and families by addressing healthcare access and affordability
- The importance and opportunity for including patient and caregiver insights in all aspects of health services research
- The advocacy role people can play to support patient and caregiver needs in their communities

In this year's Patient Congress, Maurine "Mo" Stuart of Snowshoe, WV, was recognized by her peers as the Donna Guinn Outstanding Volunteer for her exceptional work helping people with epilepsy access affordable and equitable care, specifically in the areas of care planning and healthcare affordability.



PAF EVP Alan Richardson, Congressman Bobby Scott and PAF CEC Alan Balch at PAF's 20th annual Promise of Hope gala.

Promise of Hope

PAF's Promise of Hope Affair was held as an elegant outdoor and virtual hybrid event. The event raised \$137,500 in support of patients served through our case management programs and \$101,000 for the Scholarship for Survivors program. Speakers included Dr. Benton Brown, a surgeon and past scholarship recipient. Guests also enjoyed the live and silent auctions, dinner and dancing under the stars.

25 event sponsors

\$238,500 raised

31 scholarships funded

To learn more, please visit **promiseofhope.net**



Fundraising Event Champion

We would like to extend our gratitude to Dr. Herman Kelly and recognize him as PAF's 2021 Fundraising Event Champion. Dr. Kelly is a pastor of Bethel African Methodist Episcopal Church in Baton Rouge, professor of African Studies at Louisiana State University and an avid swimmer. In May 2021, he raised funds and awareness in support of cancer patients through a Swim for Life campaign.

Dr. Kelly's wife, Linda, was undergoing cancer treatment and her oncology clinic recommended PAF as the recipient for his fund-raising efforts. Together with his supporters, **Dr. Kelly raised \$10,000 in support for PAF** through its *Challenge Your Own Fundraiser Event* platform. Sadly, Linda lost her battle with cancer. Dr. Kelly plans to host the *Swim for Life* event annually in her memory.

To learn more on how you can host a PAF fundraising event, visit patientadvocate.org/champion-your-own-fundraising-event/

Scholarship for Survivors

For more than 20 years, our Scholarship for Survivors (SFS) program has supported deserving college students whose educational pursuits were threatened or disrupted due to a chronic illness. To date, 135 students have received **scholarship awards totaling more than \$823,000**. PAF, along with many other gracious funders, has enabled 54 accomplished and courageous young adults to graduate with a college degree. Nine new awardees and 22 returning students received a scholarship this academic year valued at \$3,000 per school year for four consecutive years.

Learn more about our students and enjoy their audio messages at **tiny.cc/2021 studenthighlights**



For more about our scholarship program, visit **patientadvocate.org/scholarships**



"Just before I started my junior year of high school, I was diagnosed with stage 4 Hodgkin's Lymphoma. I received extensive chemotherapy and radiation. Though it was hard, I pushed through and even found a passion for physics, specifically in the field of radiology. This discovery led me to the path that I am currently taking in pursuing my Bachelor's in Physics. Being sick was incredibly difficult, however, it shaped my life for the better in so many ways. It is my hope that I will someday be able to help kids in the same position I was in and show them that there is a life beyond cancer. Thank you for your support!"

- Allison | Scholarship Recipient



A Message from Lydia PAF scholarship recipient and fourth year medical school student



tiny.cc/paflydia

Financial Statements

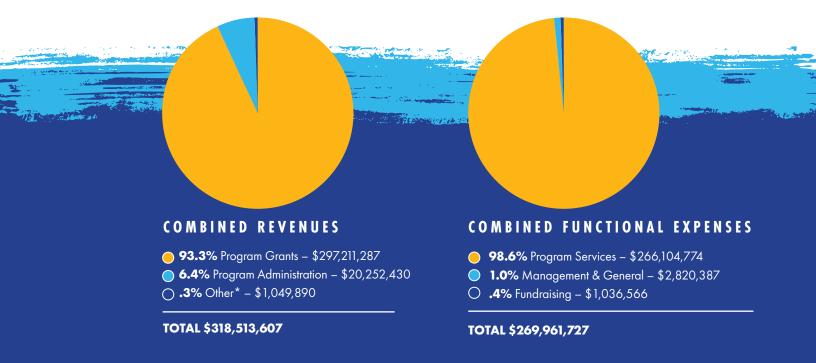
PAF financial statements are based on its fiscal year, from July of 2020 to June of 2021. The program impact reporting in the preceding pages is conducted on an annual basis, from January 2021 to December 2021.

SUMMARY OF TOTAL PATIENT IMPACT IN FISCAL YEAR 2020/21

Total Patient Cases	149,564
Total Case Management Cases	21,324
Total Co-Pay Relief Recipients	61,678
Total Financial Aid Fund Recipients	53,555
Total Patient Services Email Helpline Sessions	13,007
Total Patient Services Case Contacts	1,200,103

SUMMARY OF CASE MANAGEMENT IMPACT IN FISCAL YEAR 2020/21

Total PAF Case Management Case Count	21,366
Unique Case Management Patient Issues	24,051
Total PAF Case Management Contacts	294,386
Average Contacts per Case	14



	2021		2020
ASSETS			
Current assets General operating cash and cash equivalents Restricted cash and cash equivalents Unconditional promises to give Accounts receivable Interest receivable Due from National Patient Advocate Foundation Investments and cash equivalents Inventories Prepaid expenses	\$ 28,356,319 287,485,725 17,613,158 1,745,868 116,954 37,462 62,194,524 72,356 390,886	\$	34,643,003 172,931,062 14,086,492 1,611,627 266,096 41,713 127,186,163 55,002 471,457
Total current assets	398,013,252		351,292,615
Property and equipment, net	3,861,164		3,919,924
Other assets	50,331		50,331
	\$ 401,924,747	\$	355,262,870
LIABILITIES AND NET ASSETS Current liabilities			
Accounts payable and accrued expenses Due to National Patient Advocate Foundation Postretirement benefits liability, current portion Deferred revenue Accrued vacation leave	\$ 8,777,237 35,162 63,621 21,918,604 574,462	\$	13,105,119 52,641 48,930 19,151,391 569,698
Total current liabilities	31,369,086		32,927,779
Long-term liabilities Postretirement benefits liability, less current portion Incurred but not recorded liabilities Total long-term liabilities	2,709,676 152,603 2,862,279	_	4,148,581 135,687 4,284,268
Total liabilities	34,231,365		37,212,047
Net assets without donor restrictions Undesignated	18,853,500		16,262,233
Board designated	2,194,524		2,186,163
Total net assets without donor restrictions	21,048,024		18,448,396
Net assets with donor restrictions			
Restricted by purpose	346,645,358		299,602,427
Total net assets	367,693,382		318,050,823
Total liabilities and net assets	\$ 401,924,747	\$	355,262,870

Patient Advocate Foundation Statements of Financial Position June 30, 2021 and 2020

		2021			2020	
	Without	With		Without	With	
	Donor Restrictions	Donor Restrictions	Total	Donor Restrictions	Donor Restrictions	Total
OPERATING REVENUES						
Contributions:						4770 127 470
Grants	407'6C/'Z ¢	\$2,44,402,083	/97/117//67¢	010,838,510	\$Z/4,299,134	\$2/8,13/,0/U
Private and public donations	208,539	•	208,539	258,93/	•	258,93/
Donated services and materials	9,511		9,511	36,924	I	36,924
Program administration	20,252,430	•	20,252,430	18,618,857	•	18,618,857
Patient Congress	65,000	•	65,000	70,000	ı	70,000
Promise of Hope				123,770	ı	123,770
Patient Action Council	75,000		75,000	125,000	ı	125,000
Investment return, net	691,840		691,840	3,882,221	I	3,882,221
Net assets released from restrictions:						
Satisfaction of program restrictions	247,409,152	(247,409,152)	'	238,734,798	(238,734,798)	ı
Total revenues, gains and other support	271,470,676	47,042,931	318,513,607	265,689,023	35,564,356	301,253,379
OPERATING EXPENSES						
Program services:						
Patient/ educational services	5,615,958	ı	5,615,958	5,575,996	I	5,575,996
Financial aid programs	254,199,499		254,199,499	246,082,505	I	246,082,505
Service contracts	6,289,317	•	6,289,317	6,044,175		6,044,175
Supporting services:						
Management and general	2,820,387		2,820,387	2,860,826		2,860,826
Fundraising	1,036,566		1,036,566	1,085,844		1,085,844
Total expenses	269,961,727	I	269,961,727	261,649,346	ı	261,649,346
Change in net assets from operations	1,508,949	47,042,931	48,551,880	4,039,677	35,564,356	39,604,033
OTHER NONOPERATING CHANGES Postretirement benefit changes other than periodic cost	1,090,679		1,090,679	(942,934)		(942,934)
Change in net assets	2,599,628	47,042,931	49,642,559	3,096,743	35,564,356	38,661,099
Net assets, beginning of year	18,448,396	299,602,427	318,050,823	15,351,653	264,038,071	279,389,724
Net assets, end of year	\$ 21,048,024	\$346,645,358	\$367,693,382	\$ 18,448,396	\$299,602,427	\$318,050,823

Patient Advocate Foundation Statements of Activities Years Ended June 30, 2021 and 2020

FINANCIAL STATEMENTS

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