

South Carolina Cancer Alliance

Patient Advocate Foundation Overview



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Our Mission

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

Our History

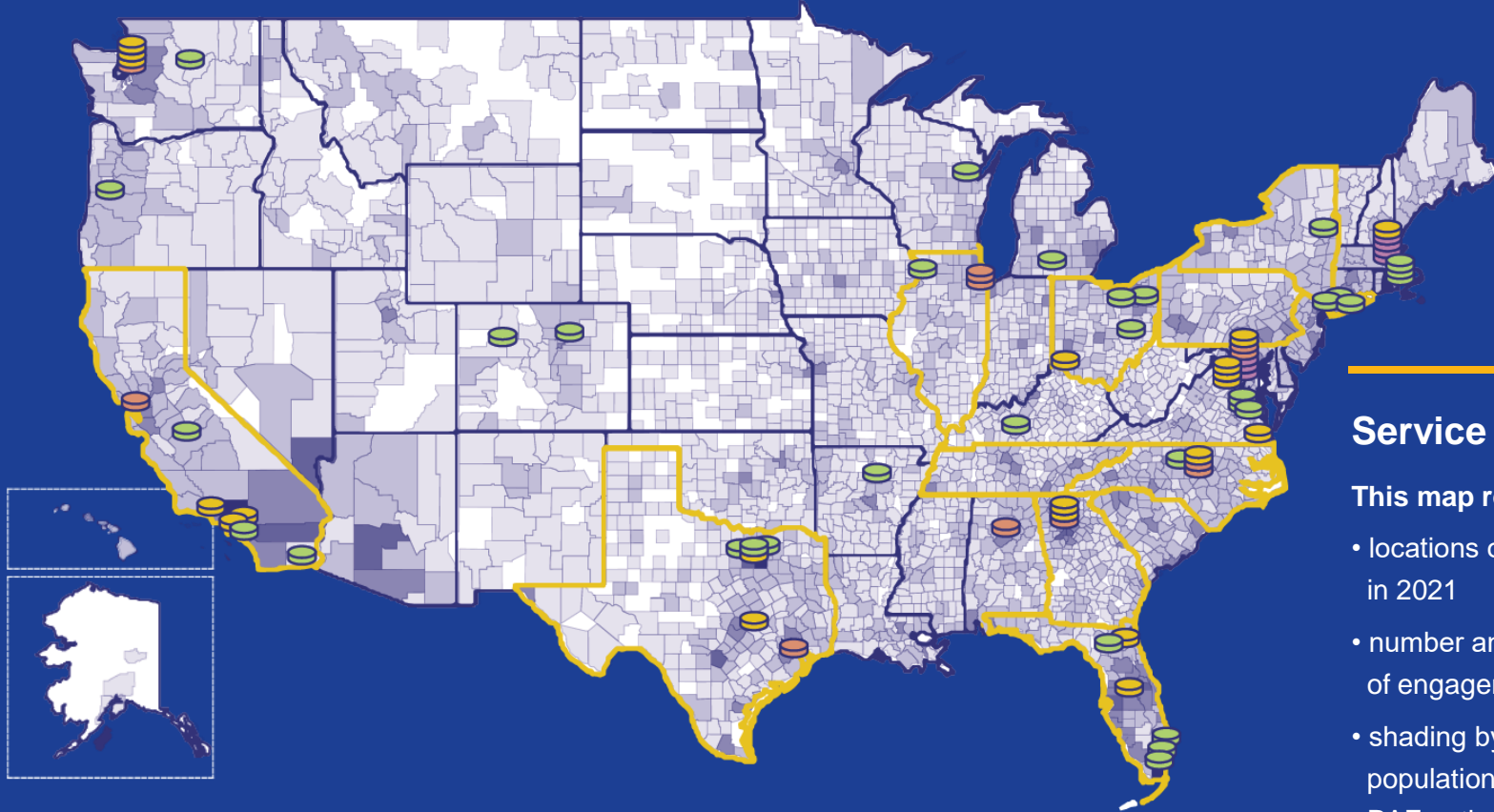
PAF was founded in 1996 by Nancy Davenport-Ennis and co-founded by John H. (Jack) Ennis to help address the issues faced by patients like their friend Cheryl Grimm, who had to battle not only her breast cancer but for access to affordable treatments. In PAF's first year, Nancy and a part-time volunteer 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.



It Starts with the Patient

“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.”

Alan J. Balch, PhD
Chief Executive Officer



Service to All 50 States

This map represents:

- locations of patients served in 2021
- number and type of engagement activities
- shading by county depicts population density of PAF patients
- top ten patient service states

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% |

patientadvocate.org

PAF Patient Advocate Foundation

Overall Foundation Impact

Summary of PAF Total Patient Cases and Contacts 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

748

DISTINCT PATIENT DIAGNOSES

337

DISTINCT RARE DISEASES

INCREASED
by 37% over 2020

What Our Patients Are Saying...

PAF uses a standardized survey to assess overall patient satisfaction and program impact levels. Each patient directly served by the organization is invited to share feedback in either English or Spanish.

2021 Overall Patient Satisfaction Rating

9 of 10

Patient Ratings for PAF Service

4.6 of 5

knowledge & professionalism of staff

93%

indicated that PAF
provided valuable help

94%

would recommend
PAF to others

Patient Advocate Foundation Engagement Areas



Case Management



Co-Pay Relief Program



Financial Assistance
Funds



Patient Education
& Communications



Health Equity &
Community Engagement



Patient Impact



Special Events



Health Services,
Research, Patient
Experience & Evaluation

PAF Responds to COVID-19

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.

"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

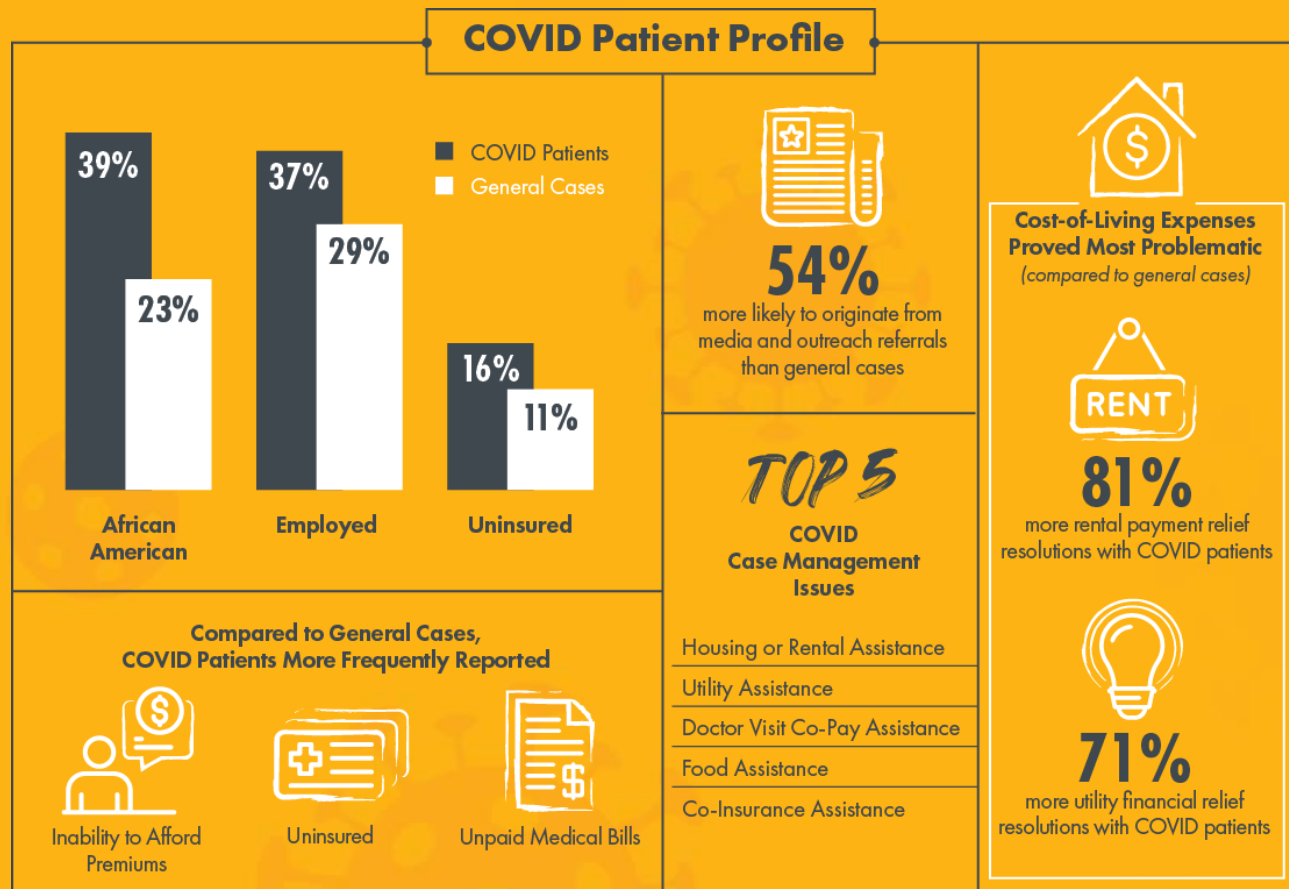
In 2021, PAF assisted COVID-19 patients through multiple programs and resources including:

- **COVID Care Resource Center**
 - COVID Care Webinar Series
 - COVID Care Resource Directory
- **COVID Care**, case management support program
- **PAF's Co-Pay Relief COVID-19 Fund**



2021 COVID Case Management Service by the Numbers

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.



An impressionistic painting of a harbor scene at sunset. A tall, dark lighthouse stands on a rocky outcrop in the foreground on the right. In the center, a large sailboat with dark sails is on the water. The sky is filled with vibrant, blended colors of orange, yellow, pink, and blue, suggesting a sunset or sunrise. The water reflects these colors. In the background, other ships and a distant shoreline are visible. The overall style is painterly and expressive.

HOW WE HELP

> Real World Experiences

Patient Eligibility Requirements

Are You Eligible?

- You must have a confirmed diagnosis of a serious health condition or getting testing for the condition.
- Be in active treatment for the health condition, including active surveillance or follow-up.
- Be a U.S. citizen or a permanent resident of the United States.
- Be receiving treatment in the United States or a U.S. territory.
- Need help with an access or affordability issue that is related to their diagnosis.

Case Management: What We Focus On

Reducing Financial Burden

- Identifying local, regional, and national resources for financial support for living expenses such as housing, utility, transportation, food
- Educating and connecting to specific programs that address loan deferral or forgiveness programs for mortgages, car loans, personal loans, credit cards, and student loans
- Educational and emotional support resources including online support groups, nutritional and wellness resources
- Education on ADA and FMLA rules and regulations
- Assistance engaging, applying, and appealing workplace benefits including short-term and long-term disability

Enrollment in Appropriate Insurance, Charity, and Social Programs

- Eligibility and enrollment into Medicare, Medicaid, social security disability, ACA products, insurance, charity care, negotiation of payment plans or discounts for medical care
- Evaluate eligibility and facilitate application to charity care and discount programs
- Review of employment status (if applicable) and provision of education and support to access unemployment benefits and/or sick and FMLA paid time off

Providing Insurance Navigation

- Insurance utilization assistance such as benefit review, preauthorization, clinical appeals, billing and coding issues, out-of-network, second opinions, and treatment decisions including clinical trial screening, insurance plan interpretation
- Facilitate insurance appeal process for denied treatment and medications

PAF Case Managers cannot help with:

Non-U.S. Lawful Resident or Treatment outside the United States. PAF cannot support:

- Requests for help accessing treatment outside of the United States.
- Patients who are not legal permanent residents of the United States.

Financial Assistance. PAF cannot:

- Provide direct financial assistance.
- Negotiate to resolve a medical bill older than 1 year.

Legal representation and/or accident/work-related compensation. PAF cannot provide support for:

- Cases that are in active litigation and/or have retained counsel.
- Requests for personal recommendations or referrals for legal representation.
- Worker's compensation.
- VA Benefit eligibility and ratings.
- Victim Compensation Funds or class action lawsuits.

PAF Case Managers cannot help with:

Medical Provider/Facility Disputes or Medical Advice. PAF cannot provide support for:

- Disputes resulting from a provider releasing/terminating a patient from their practice.
- Requests for us to ask a medical provider/ facility to accept a patient or insurance.
- Dissatisfaction with patient rights or claims for malpractice or negligence.
- Dissatisfaction with an in-patient facility, or coordinate transfers due to dissatisfaction.
- Mental health services, counseling, or psychiatric hospitalization admissions assistance.
- Recommendations for specific providers, facilities, treatment; or express any medical opinion.
- Disputes with a provider related to diagnosis, treatment options, or medication frequency or dosage.

Health Insurance Benefit Disputes and Exclusions. PAF cannot support for:

- Insurance appeals for payment to a specific facility/doctor, medication or treatment *that is not medically supported*.
- Insurance appeal or financial support for medical marijuana or CBD products.
- Insurance appeal or financial support for holistic medicine or homeopathic treatment.

2021 Case Management Service by the Numbers

20,374

TOTAL CASE COUNT

317,089

TOTAL CASE MANAGEMENT CONTACTS

16

AVERAGE CONTACTS PER CASE

\$23M+

in debt relief obtained on
behalf of patients

34

case management programs
in 2021, 4 were new and 16
programs were administered
by PAF for other non-profit
organizations.

TOP 10 DIAGNOSIS CATEGORIES SERVED BY CASE MANAGEMENT



Cancers



Chronic or
Debilitating
Conditions



Nervous
System
Conditions



Cardiovascular
Conditions



Vascular
Diseases



Autoimmune
Diseases



Diabetes



Pulmonary
Conditions



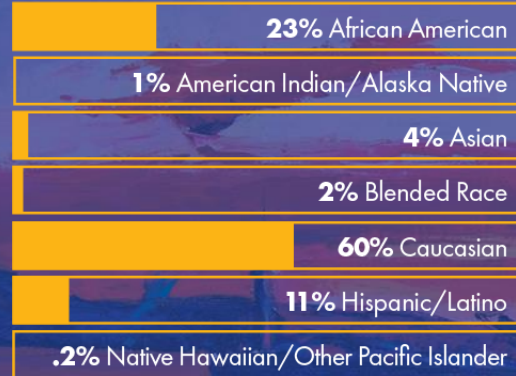
Infectious
Disease
Conditions



Gastrointestinal
& Hepatology
Diseases

Case Management Demographics

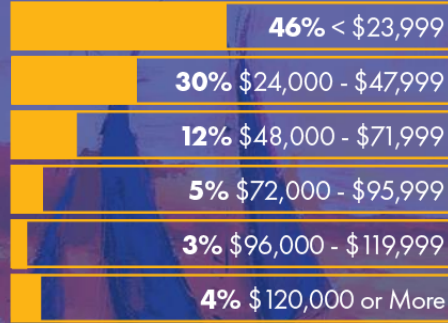
ETHNICITY



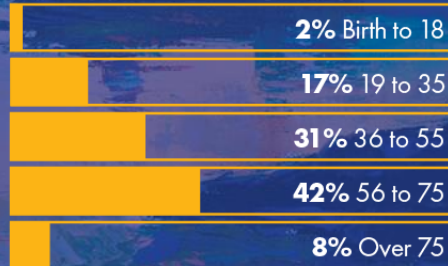
INSURANCE STATUS



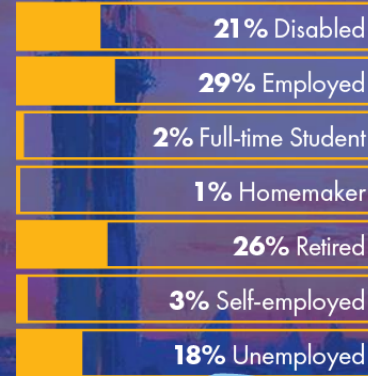
INCOME



AGE



EMPLOYMENT

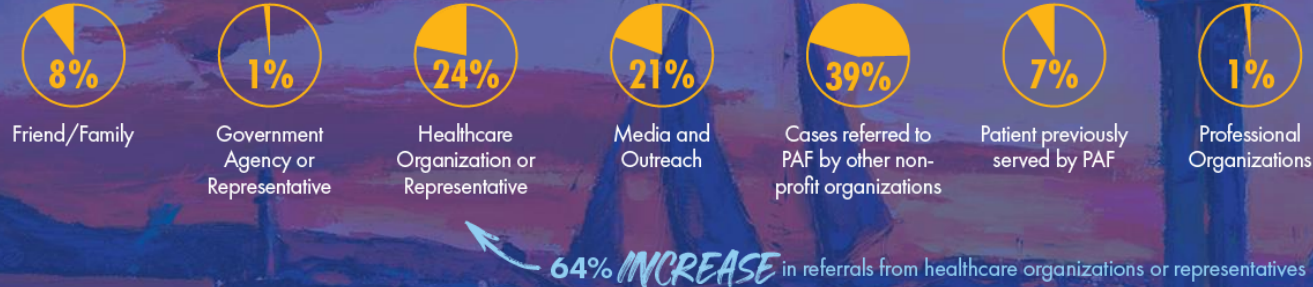


10% INCREASE
in the retired category

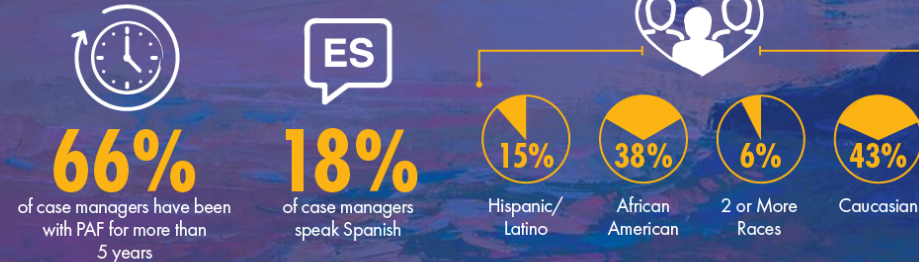
11% INCREASE in patients over 75

Case Management

HOW PATIENTS FIND PAF CASE MANAGEMENT SERVICES



CASE MANAGEMENT STAFF



TOP WAYS PAF CASE MANAGERS HELPED PATIENTS

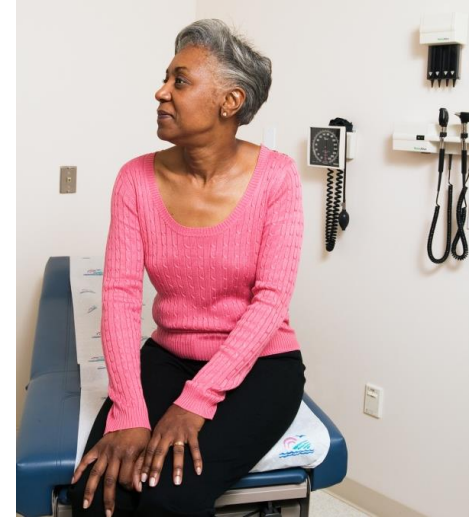
8%	Obtained utility financial relief
7%	Located rental payment relief
7%	Facilitated assistance with out-of-pocket medical costs
6%	Educated on disability eligibility and enrollment
5%	Educated on health insurance eligibility and enrollment
4%	Negotiated discount on out-of-pocket medical costs
4%	Negotiated payment plan for medical bills

Case Management

CASE EXAMPLE

60-year-old African American Female

- Diagnosed with Breast Cancer
- Insured through her employer, but the company is being sold and her insurance will expire in 30 days. No coverage being offered by the new owner
- Patient will begin radiation in the coming weeks and will not be able to afford the out-of-pocket cost of treatment
- Limited income and she reports that she is unable to afford insurance coverage



Patient: PAF/64549-14

Case Management

How did PAF Case Management Help?

- ✓ Determined that the patient qualified for special enrollment in a Marketplace Plan
- ✓ Verified qualification for premium subsidy of \$541
- ✓ Determined “Silver Plan” would meet the patients treatment needs and fit in her budget
- ✓ Confirmed that she qualified for “out-of-pocket” subsidy reducing her annual deductible from \$3,350 to \$200 and her out-of-pocket max from \$5,500 to \$650
- ✓ Arranged and coordinated FMLA to cover her half-day appointments
- ✓ Initiated Short-Term Disability with her employer
- ✓ Coordinated a transportation grant
- ✓ Facilitated enrollment into a co-pay assistance program to cover her oral medication costs
- ✓ Facilitated an application for grant funding from a local Breast Cancer Foundation to cover utility costs
- ✓ Facilitated an application to a charitable fund that contributed \$300 toward outstanding medical and physician bills



Patient Impact

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. He is on track to begin lifesaving chemotherapy in the next 5 days."

-Edie's Sister



Healthcare Impact

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



43%

reported they had trouble covering healthcare expenses before and during pandemic



17%

reported that pandemic-related employment change impacted health insurance coverage



77%

reported health insurance impacts stopped or delayed medical care



15%

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

Patient Impact

Karen | Colorectal Cancer

"My case manager was a tremendous help to me and my family! 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 cancelled, 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 PAF has truly been a blessing to me!"

-Karen



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



Patient Advocate Foundation

CO-PAY RELIEFSM


DISPENSING HELP, DELIVERING HOPE

patientadvocate.org

PAF Patient Advocate
Foundation

Co-Pay Relief Program: Service By The Numbers

PAF recognizes that many patients cannot adhere to prescribed medical care without financial help. Our Co-Pay Relief (CPR) program provides direct financial assistance for co-payments, co-insurance or cost-sharing to qualified patients through funds dedicated to specific disease states.



60,536
Patients Approved



6
Average Contacts
per Approved Applicant



176,549
Incoming Calls Handled



701,926
Total # of Grant Payments



\$240,511,901
Grant Payment Total

Patients Served by CPR Since 2004

582,072



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

Application Process

Instant Eligibility Decisions

- Applicants receive an instant eligibility decision at the time of submission based on the information supplied and availability of funding.

Electronic Income Verification

- Electronic income verification performed on all patients reported income, eliminating document submission in >95% of applications

Best in Class Compliance and Highest level of patient qualification review

- Complete income review of 100% of patients approved for award
- All patients diagnoses & insurance are verified with treating physicians by PAF's CPR staff

Personalized assistance for the Patient, Provider and Pharmacy web-based portals

www.CoPays.org

Toll-Free number to CPR application Staff

866-512-3861



Portals available 24 hours a day



Electronic signature capability



Document upload and fax import

Expenditure Process

Expenditure Submission

Virtual Pharmacy Card: the virtual pharmacy card may be used at pharmacies or specialty pharmacies

Pharmacy / Provider / Patient Portals: expenditures may be submitted through the portals, where the patient, pharmacy, and provider can upload expenditures directly.

Mail / Fax: claims may be made through mailing or faxing expenditures with the patient's unique barcode cover sheet.

Portal, Mail, and Faxed Expenditures processed for payment daily and can be paid via EFT or by check

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FINANCIAL SERVICES

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.



9
new financial assistance
funds launched in 2021



324,176

grant payments made to patients,
a **26% increase** over 2020



243,783

incoming calls handled
by our financial call counselors

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.

Patient Impact

Romelia | Breast Cancer

"Thank you for approving my grant. I currently have stage 4 metastatic breast cancer and 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."

-Romelia




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 work-related income

An impressionistic painting of a harbor scene at sunset. A tall, dark lighthouse stands on a rocky outcrop in the foreground on the right. In the middle ground, a large sailboat with dark sails is positioned in the water. The background shows a distant shoreline with other boats and buildings under a sky filled with vibrant, blended colors of orange, yellow, and purple. The overall style is painterly and expressive.

HEALTH EQUITY & COMMUNITY ENGAGEMENT

Patient Partner for Equity

Since our inception 25 years ago, Patient Advocate Foundation (PAF) has been the voice for the voiceless, navigating the complex healthcare and insurance coverage systems to enable patients to gain access to life changing treatments.

We have seen firsthand the effects social determinants of health have on healthcare access, healthcare quality, and affordability manifesting as social and financial need gaps to insurance and safety net programs designed to help patients avoid financial devastation and poor health outcomes.

WHEN PAF PATIENTS WERE ASKED...

63%
OF PATIENTS

experienced financial hardship
in the past year due to the costs
of their medical care
(PAF 2018 Cost-of-Care Survey)

34%
OF PATIENTS

reported that challenges
with insurance coverage was
a barrier to achieving their
healthcare goals

58%
OF PATIENTS

reported that out-of-pocket
medical costs were a
significant barrier to achieving
healthcare goals
(PAF 2019 Retrospective Survey)

78%
OF PATIENTS

stated that PAF assisted
them in achieving their
healthcare goals

32%
OF PATIENTS

stated that out-of-pocket costs
were a major factor when
selecting treatment options
after diagnosis
*(2019 Impact of Disease
Diagnosis on Employment Survey)*

40%
OF PATIENTS

reported being
"very concerned" about
having access to the best
medical care during their
treatment journey

Health Equity & Community Engagement



PAF's SelfMade Health Network (SMHN) implements evidenced-based strategies, including training and technical assistance, to address cancer- and 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

Men's Health: The Intersection of Cancer Survivorship, Health Equity, Socioeconomic Factors



"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

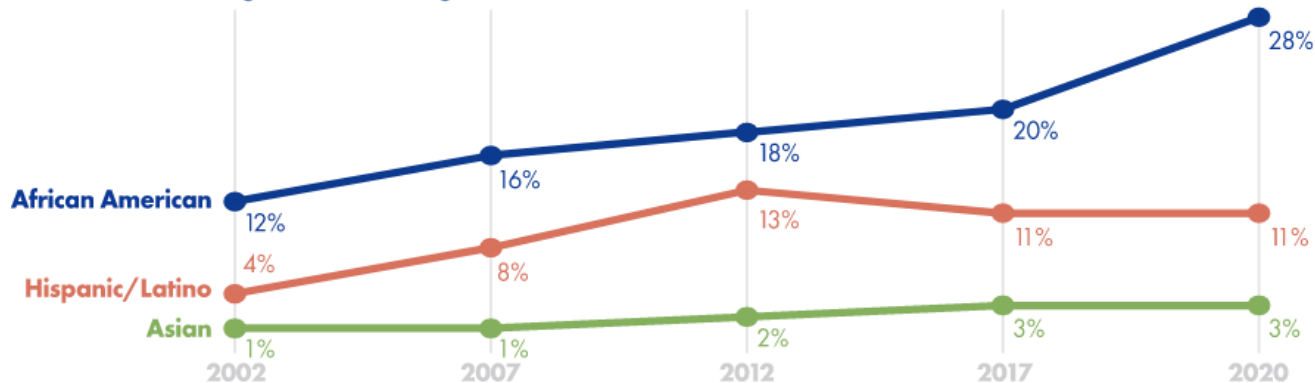
SMHN aligned efforts with 2 fellow national networks to launch the Tri-Networks HPV Learning Collaborative. This project was selected and published by the CDC as a success story: **National Networks Come Together to Help Prevent HPV-Related Cancers**

tiny.cc/HPVcancerprevention

Health Equity & Community Engagement

Since inception, PAF's work has focused on addressing health inequities driven by our service to specific populations experiencing high premature mortality in part because of social determinants of health, or, more specifically, the gaps caused by them.

PAF's Progress in Reaching Underserved Patients



PAF Health Equity Accomplishments

>1,750

Patients and caregivers reached through three innovative, collaborative outreach events focused on breast cancer with topics ranging from breast cancer screening and treatment to financial resources and PAF services.



10k

Estimated viewers reached with lymphedema educational video produced in partnership with Live Today Foundation

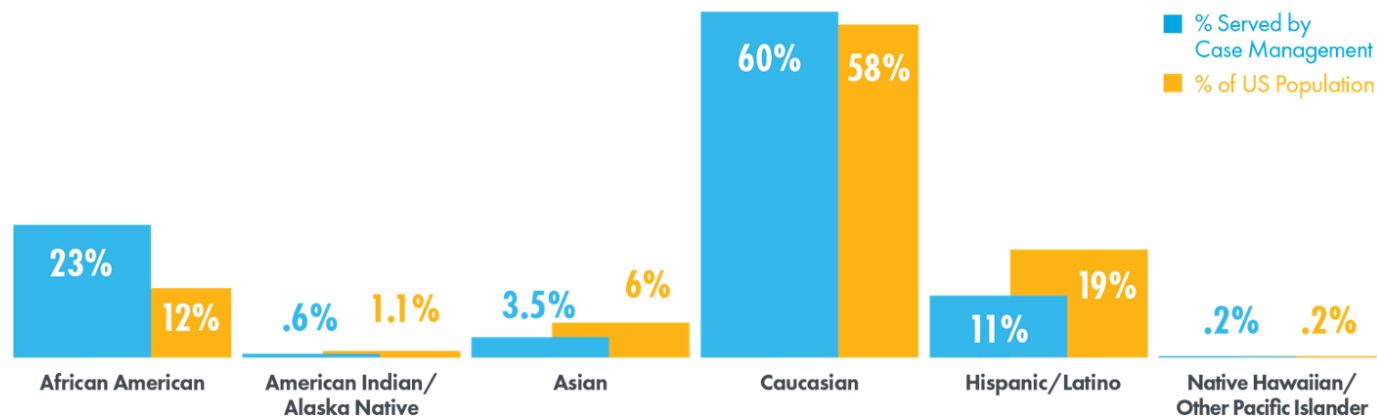


Through SelfMade Health Network, collaborated with the Memphis Breast Care Consortium for video production to educate Black women on what it means to have a breast cancer diagnosis

Health Equity & Community Engagement

PAF's commitment to addressing health equity is a guiding philosophy that informs program design, planning and implementation across the organization.

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



Virtual outreach environment enabled reach to 3,650 individuals across the country and engagement with:

Providers in the cancer community to develop strategies to prioritize cancer equity

Researchers to explore opportunities to include racial and ethnically diverse populations in clinical trials

Fellow advocates to integrate equity-centered approaches for persons living with rare diseases

Health Equity Goals

Expand the degree to which PAF and NPAF programs and services effectively reach and serve the most vulnerable patients facing inequities in the health care system in a way that:

- 1) increases their opportunity to attain the highest level of health by addressing their access and affordability challenges;
- 2) produces data and patient stories that enable advocacy and research activities to expose social needs gaps.

A geographically targeted approach based on data to get assistance to those people who need it the most.

Call to Action from the CDC

- In November of 2020, the CDC announced a new social determinants of health (SDOH) module to help identify under-resourced areas of the United States.
- The new tool is intended to help researchers and public health professionals identify and better align available resources to address the needs of people at risk...
- The social vulnerability index (SVI) helps to identify communities with limited resources.
- Research shows that interventions that improve socio-environmental conditions can lead to better health and reduce health disparities.

Social Vulnerability Index

Four central themes and 15 variables:

- **Socioeconomic status:** below poverty, unemployed, income, no high school diploma
- **Household composition and disability:** persons over age 65, persons under age 17, persons over age 5 with a disability, single-parent households
- **Race/ethnicity and language:** minority status, ability to speak English “less than well”
- **Housing or transportation status:** multi-unit structures, mobile homes, crowding, no vehicle ownership, group living quarters

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Identifying Counties with Highest Social Needs

- PAF used a reasonable, uniform and verifiable way to identify a set of counties who have extreme need for financial support based on disease burden and social vulnerability – both broadly defined using multiple criteria.
- Process for identifying counties included the use of
 - The CDC SVI index is 15 variables spanning 4 themes.
 - Socioeconomic status
 - Household composition and disability
 - Race/ethnicity and language
 - Housing or transportation status
 - Similarly, PAF created a chronic disease index spanning 17 variables in 4 disease areas
 - Diabetes prevalence
 - Cancer incidence rates in 5 racial and ethnic groups
 - CVD deaths in 5 racial and ethnic groups
 - HIV prevalence in 6 racial and ethnic groups.

Identifying Counties with Highest Social Needs: Methodology

- Identified all counties with a SVI score of ≥ 90
- Identified all counties that hit established CDC cut point (either top 25% if quartile breaks or top 40% if quantile breaks) for :
 - all 4 disease areas OR in 3 of the 4 disease areas or;
 - with high rates of disease burden in 3 or more racial and ethnic groups
- Identified the top 100 counties in the country in each disease area with SVI score of $\geq .90$
- Identified all counties not already included whose populations of American Indians and/or Alaskan Natives are greater than 33% of the total population and who score at least a .75 on the SVI.
- Analyzed included counties with larger populations (population $\geq 400,000$ or land areas $\geq 3,000$ sq/mi)
 - Zip codes within those counties were included if they met income criteria thresholds according to at least two income measurement areas: Median Family Income, Median Household Income, Average Household Income (2000 Census).

Health Equity Initiative

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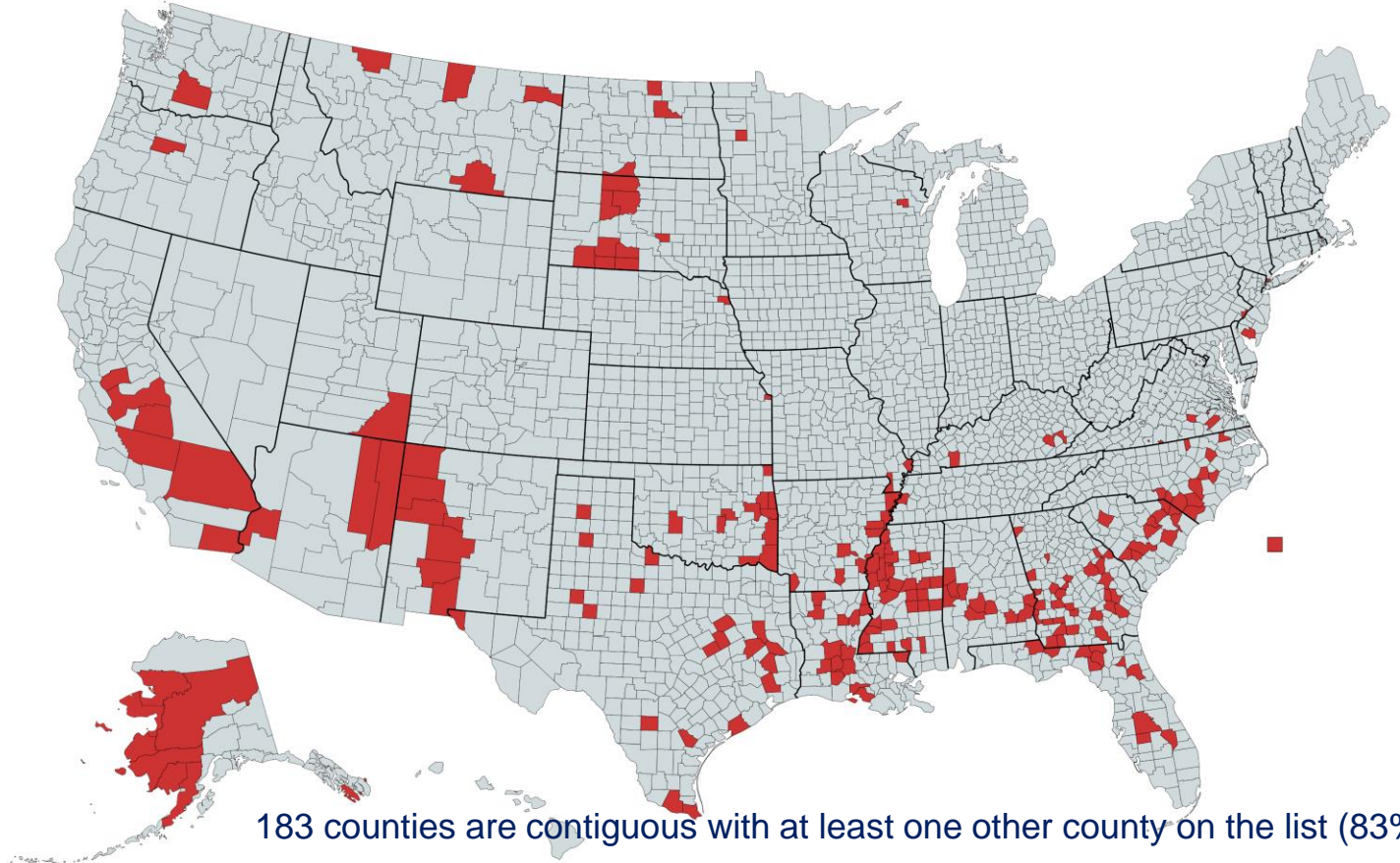
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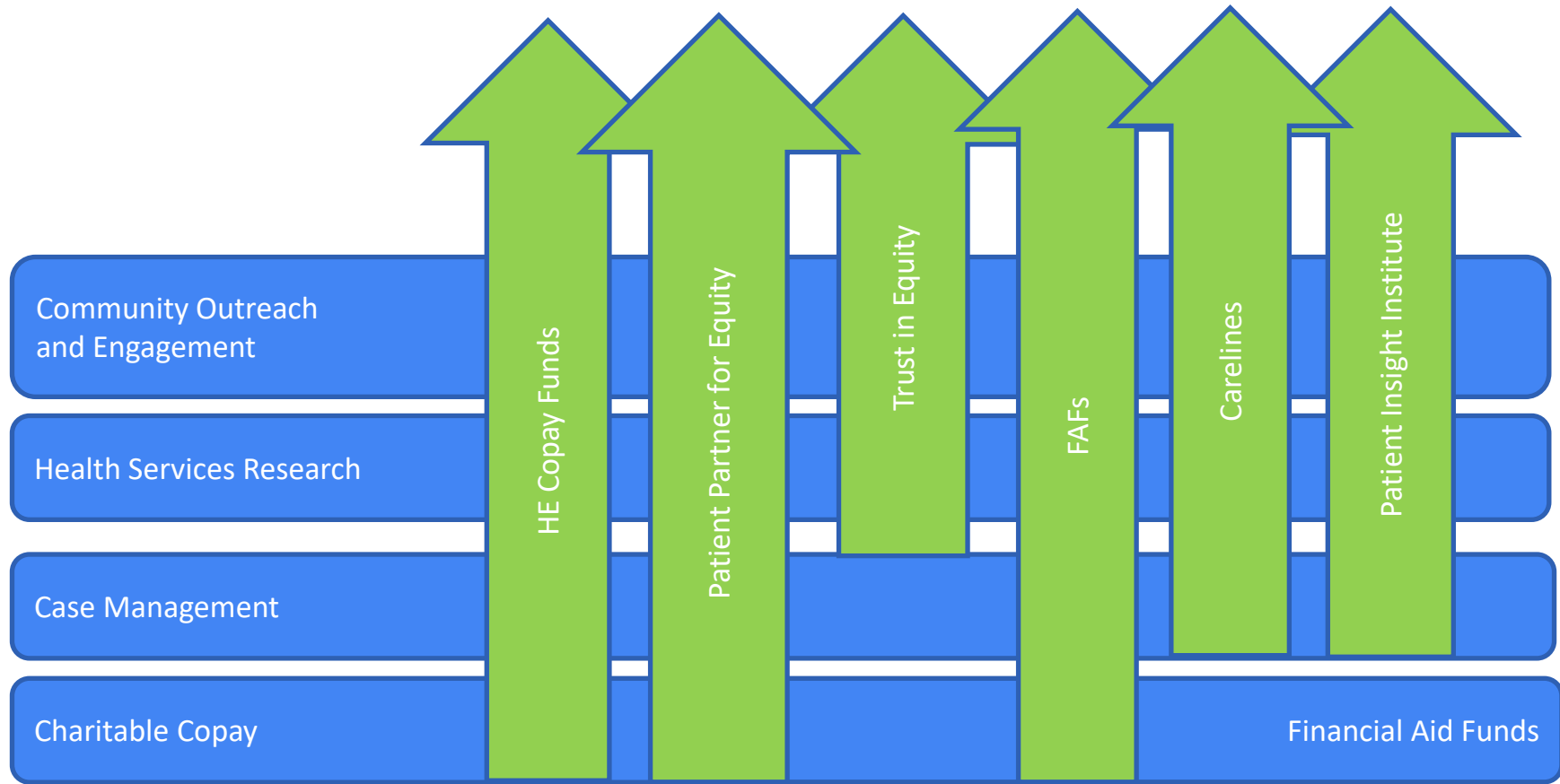
reported being
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Identifying Counties with Highest Social Needs: Outcome

220 counties have been identified as priority areas



183 counties are contiguous with at least one other county on the list (83%)



Health Equity through Community Engagement

We want to further expand our reach into the communities that continue to experience healthcare inequities as we know that there is still much work to do.

Our experience has taught us that the **path to equity and access** is through interconnectedness.



“We can reduce health disparities and better connect people to high-quality medical care, but to really make a difference, we need to address the social determinants of health and equity that protect some people and push others off the cliff.”

**- Camara Phyllis Jones,
MD, MPH, PhD**

Better Together: A Collaborative Model to Address Health Equity

Our goal is to expand the degree to which PAF programs and services effectively reach and serve diverse patients in a way that facilitates their opportunity to attain the highest level of health, produces data and patient stories that enable advocacy and policy activities to address social needs gaps.



One-to-One relationship between PAF
and other nonprofit organizations



Bidirectional relationship allows us
to close the gap of health
inequities for some patients



Education and tools necessary to
connect patients/families/
caregivers to disease resources
including patient support programs

Patient Partners for Equity

Patient Partner in Equity - Features

As a member of PAF's Patient Partners for Equity program, organizations will receive the following benefits:

- **Recognition of organization:** Organization's logo and mission statement listed on our [Patient Partner for Equity](#) webpage.
- **Personalized Education Session:** We provide personalized education to participating organization's staff about PAF's patient support and educational services, including how to refer patients who need help.
- **PAF E-communications & Newsletters:** We provide organizations regular communications from us including the Patient Partner for Equity Newsletter, [PAF Spotlight](#), NPAF Policy Dispatch Newsletter and other patient focused patient resources, public policy updates and events.
- **Policy Consortium:** Organizations receive a complimentary virtual membership to National Patient Advocate Foundation's (NPAF) [Policy Consortium](#).
- **Partner Spotlight:** We want to share our partner's successes on PAF's websites once per year on our [Patient Partner for Equity Page](#).

Patient Partner in Equity - Features

As a member of PAF's Patient Partners for Equity program, organizations will receive the following benefits:

- **PAF's Patient Partner Portal (Available late 2023):** We want referring to us to be as easy as possible and we want to provide organizations access to information about the referrals they make. To accomplish this, we are building a **dedicated online portal exclusively for nonprofit organizations** to access our patient programs and educational resources in a centralized location! The portal will allow non-profit organizations access to:
 - PAF's [Case Management](#) portal to submit a referral to our team
 - PAF's [Co-Pay Relief](#) program, enables organizations to apply for financial assistance on behalf of patients who meet eligibility requirements, track the activity of patient grants, assist with reapplications or submission of materials as needed and gather insights on how these grants impacted the lives of patients seeking their support.
 - [PAF's Educational Resource Center](#) connects organizations instantly to our publications, webinars, tip sheets, and interactive tools. Our educational library allows users to search, and filter based on the information they need. Learn about insurance, disability, appeals, medical bill management, and more!

Patient Partner for Equity – Priority Disease Areas (Phase I)

- Breast Cancer
- Cervical Cancer
- Cystic Fibrosis
- HIV
- Pulmonary Fibrosis
- Melanoma
- Multiple Myeloma
- Myelodysplastic Syndromes
- Sickle Cell Disease
- Spinal Muscular Atrophy

Ready to be a Patient Partner for Equity?

Participation is simple. We ask for an organization's commitment to participate through the completion of the Patient Partner for Equity profile form, allow us an opportunity to provide training to their team(s) about our patient support programs and agree to be included as a **Patient Partners for Equity** member on PAF's websites.



The screenshot shows the Patient Advocate Foundation (PAF) website. The header includes the PAF logo, a "Donate" button, a phone number (800) 532-5274, and links to the Media Center, Facebook, and Language. The main content area is titled "Patient Partners for Equity" with the subtitle "A Collaborative Partnership Model to Address Health Equity". Below this, a paragraph explains the program's purpose: "We have seen firsthand the effects social determinants of health have on healthcare access, healthcare quality, and affordability manifesting as social and financial need gaps to insurance and safety net programs designed to help patients avoid financial devastation and poor health outcomes. The PAF Patient Partner for Equity program serves to amplify the impact non-profit patient advocacy organizations collectively have in the lives of patients and communities who continue to experience healthcare inequities, facilitating opportunities to attain the highest level of health, while producing data and patient stories that enable advocacy and policy activities to address social needs gaps."

As a member of PAF's Patient Partners for Equity, your organization will receive the following benefits:

- Recognition of your organization as a Patient Partner in Equity on PAF's websites including your logo, an organizational profile, and reciprocal links between our website and yours.
- Personalized education about PAF's patient support and educational programming delivered to your team(s) virtually in live and recorded formats.
- Regular partnership e-communications including the PAF Spotlight, NPAF Policy Dispatch Newsletter and other patient focused resources, public policy updates and events.
- Complimentary virtual membership to [National Patient Advocate Foundation's \(NPAF\) Policy Consortium](#)
- Spotlight of your organization on PAF's websites once per year



<https://www.patientadvocate.org/patient-partner-for-equity-program>

An impressionistic painting of a harbor scene at sunset. A tall, dark lighthouse stands on a rocky outcrop in the foreground on the right. In the center, a large sailboat with dark sails is on the water. The sky is filled with vibrant, blended colors of orange, yellow, pink, and blue, reflecting on the water's surface. In the background, other ships and a distant shoreline are visible under the warm glow of the setting sun.

PATIENT EDUCATION & COMMUNICATIONS

Patient Education & Communications

PAF's education initiatives provide actionable advice and guidance to patients, caregivers, and healthcare professionals with a range of topics in a variety of formats.

The Education Resource Library (ERL) houses PAF's full catalogue of educational content.

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



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



27,758
searches



633K
matching resources
provided to users

Comprehensive, interactive training series advance PAF's reach far beyond the one-on-one service delivered by our case management professionals.

846
modules completed
in 6 months

155K/year
healthcare consumers
reached by graduates

3
educational resources earned
national award recognition in 2021



Patient Education & Communications

Corporate communication activities increase awareness and utilization of programs and educational resources. We increased self-directed video production efforts in 2021, sharing the voices of PAF patients and staff.

Visit us on YouTube at: youtube.com/channel/UCHUPBQmRHOZa8SvFDFlu2dA



Written/E-Mail Communication

427,786

recipients reached
(126,774 opens)

240%

total subscriber growth

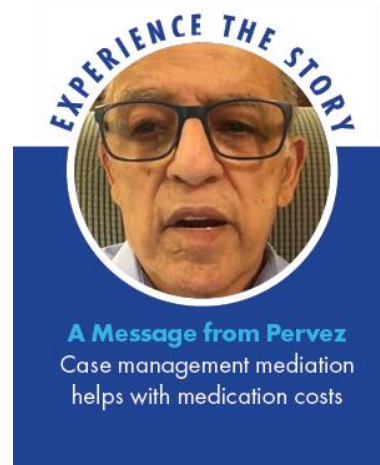
Video Communication

118%

increase in video content
engagement over past
6 months

37,443

views in 2021

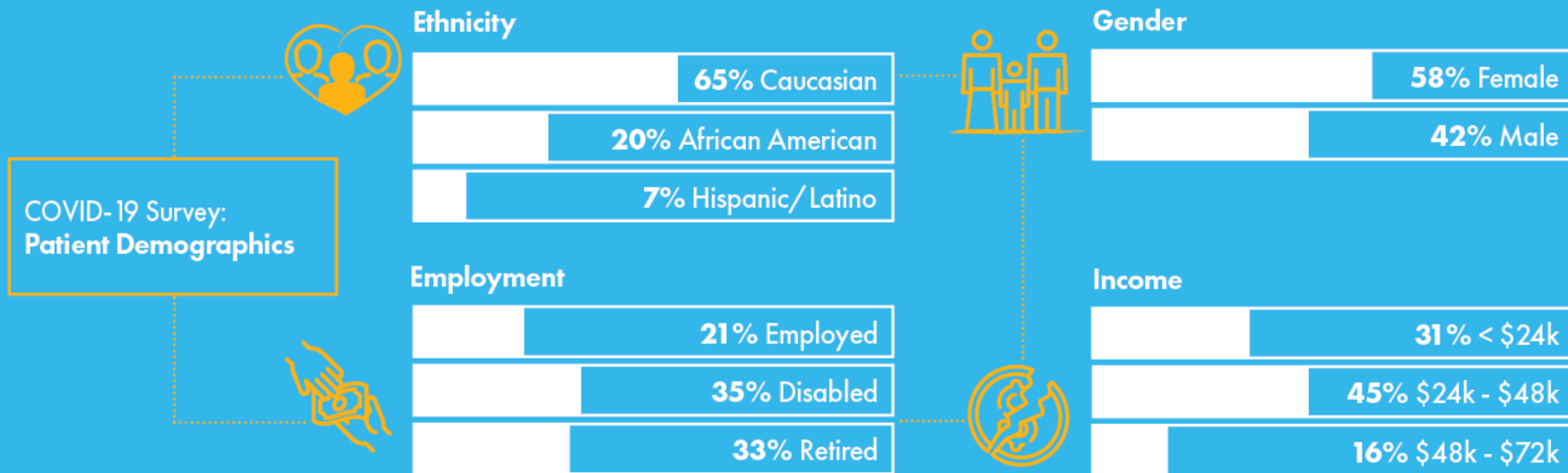


An impressionistic painting of a harbor scene at sunset. A tall, dark lighthouse stands on a rocky outcrop in the foreground on the right. In the middle ground, a large sailboat with dark sails is positioned in the water. The background shows a distant shoreline with other buildings and ships. The sky is filled with vibrant, blended colors of orange, yellow, and purple, reflecting on the water's surface. The overall style is painterly and expressive.

HEALTH SERVICES, RESEARCH, PATIENT EXPERIENCE & EVALUATION

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. 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.



Health Services Research, Patient Experience & Evaluation

PAF'S PCORI Patient Engagement

1 ***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***

Patient Insight Network survey:

- focused on patient engagement in research
- 3,000 respondents from diverse communities across every state

Initial results indicate that patients:

- want to be meaningfully involved in research development
- want to be informed about results
- believe researchers need a better understanding of the challenges low-income, uninsured, minority patients face

Patient Engagement in Research Survey: Paving a Pathway



39%

would participate in research if contacted



43%

feel they have valuable experiences to share



89%

would join a research team if tech training provided



97%

believe the patient voice and perspective is important in research

How We Shared Our Work



56%

Conference Presentations



31%

Journal Publications



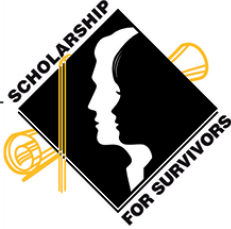
13%

Speaking Engagements

52% say they **HAVE** the tech skills required to participate

PAF's Scholarship for Survivors Program

Our Scholarship for Survivors Program supports 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.



Congratulations to the New 2021–2022 Scholarship Winners

Alexa | Duke University, Law

Allison | Washington University, Physics

Dominic | Georgetown University, Government

Lauren | Temple University, Medicine

Maia | University of New Hampshire, Nursing

Makenna | University of Washington, Communications

Maya | Worcester Polytechnic Institute, Biomedical Engineering

Meghan | Radford University, Criminal Justice

Samantha | Boston College, Biology

EXPERIENCE THE STORY



A Message from Lydia

PAF scholarship recipient
and fourth year medical
school student



“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



**National Patient
Advocate Foundation**

WHO WE ARE

- **National Patient Advocate Foundation (NPAF)**, is the advocacy affiliate of the **Patient Advocate Foundation (PAF)**.
 - **PAF** serves primarily limited-resourced patients and caregivers coping with complex chronic conditions. The direct services they provide steer people to and through available safety net programs and other assistance to reduce the burdens they experience as a result of a diagnosis.
 - **NPAF** amplifies the voices of patients and caregivers to improve how we all experience health care.

The experiences of patients and caregivers served by PAF are our guidepost and informs our advocacy.

NPAF VALUES: We believe that ...

- Patients are people first.
- Everyone should have a fair and just opportunity to be healthy.
- Patient and caregiver perspectives can improve health care.



NPAF priorities focus on:

Navigating people to safety net programs that their needs where they live.

Ensuring that access to affordable coverage and care is available for everyone.



Person-centered services that include telehealth, palliative care, psychosocial support and rehabilitation to support quality of life.

Communication and coordination that prioritizes people's needs and make them partners in care planning.

What can you do?

1. Educate your community.



Can We Talk? Workshop, Richmond 2019

- Hold information sessions to promote PAF and NPAF
- Partner with us to hold workshops: insurance access, communications skills, financial distress
- Recruit others passionate about our mission



In short, we are on track to becoming that “go to” source for patient and caregiver advocacy.

Our initiatives give our volunteers something to do with **pride**.

Our campaigns help position our volunteers as **trusted peers and leaders** in their communities.

What can you do?

2. Join our grassroots campaigns!



What can you do?

3. Engage “policy” makers.

- Cultivate relationships with legislators, health systems, decisionmakers/influencers.
- Insist on having a seat at the table!
- Be involved in health services research



Step therapy hearing, Jan 2018



TECUPP Meeting, Spring 2019



What can you do?



Advocates in Action

The Domino Effect of One Person Making a Difference



00:00 | 29:35



4. Donate your voice!

- Share your story and experience
- Help us collect stories



Story Slam, Patient Congress 2018



JUNE 19, 2020

Let My Story Be a Reminder

I had to search for his advanced care documents after he passed. What I found was paperwork showing that he had cashed out all his retirement while waiting the 3 years it took to get approved for Social Security Disability. I found credit card statements with thousands of dollars of debt on them, one still with my Mom on it.



JUNE 12, 2020

Relationships and Resources in Care Planning

I recently celebrated my seventy-fifth birthday with family. While some of the celebration was virtual, some of the family were able to visit me. During this time, the conversation turned to the present situation of Covid-19. It was a perfect time to discuss care

NPAF
National Patient
Advocate Foundation

WHAT WE OFFER



1. TRAININGS

Skills and issues-based trainings to equip you with a deeper understanding of the issues affecting patients and caregivers and how you can help advocate for change.

- **Advocacy Workshops**
 - Host a community workshop
 - Host a focus group / listening session
- **Informational Webinars (issue-based)**
- **Patient Congress**



3. COMMUNITY

Join our Facebook Group



Participate in our calls

- **Quarterly** regional calls w/ larger volunteer base (last Thursday of every quarter)



PAF – together we serve.

PAF's commitment to advancing health equity is shared by every member of our staff. We work together in service of those who are disadvantaged by social determinants of health and other challenges to ensure access – to quality healthcare services and financial support that mitigates the suffering of patients and their families.



THANK YOU



patientadvocate.org

PAF Patient Advocate
Foundation