

GUIDING PATIENTS

TO BETTER OUTCOMES

2019 ANNUAL IMPACT REPORT

OUR MISSION

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

OUR HISTORY

PAF was founded in 1996 by Nancy Davenport-Ennis and Jack Ennis to help address the issues faced by patients like their friend Cheryl Grimmel, who had to battle not only her breast cancer but for access to affordable treatments. In PAF's first year, Nancy and a part-time volunteer staff of 2 provided case management assistance to 157 patients who faced barriers to prescribed care. Fast forward to 2019, and we've helped a cumulative total of more than 1.3 million patients nationwide with support provided by more than 200 staff.

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Welcome

Since Patient Advocate Foundation (PAF) opened in 1996, we have directly assisted more than 1.3 million patients. We've learned plenty along the way, and we've taken those lessons and applied them to the broad array of programs and support initiatives PAF offers.

The patients we serve across all fifty states differ by age, ethnicity, disease condition, insurance status and access issues. However, they also have two very important characteristics in common: they want to get well, and they don't want to be financially devastated while doing so.

Some patients suffer tremendous financial consequences as a result of illness while others begin their journey already disadvantaged by their pre-existing socio-economic circumstances. Whatever the case, we know that the unique needs of vulnerable, low-income patients can be addressed with navigation to critical resources like food, housing, utilities and transportation.

We are reminded every day how much more there is to uncover about what it means to be a financially compromised patient in the world's most expensive and complicated healthcare system. What is the best place and time to uncover the issues patients face in their struggles to gain access to affordable,

high-quality healthcare? Who can discover those needs, and how? What are the interventions needed to provide help efficiently while leading to the best possible health outcomes?

Our growth this year includes not only new programs designed to address specific needs experienced by the patients who come to us for help, but also research, evaluation and reporting initiatives to advance the science of patient navigation for vulnerable populations. As reflected in this report, we are committed to sharing what we learn so that others who also endeavor to help people overcome social determinants of health and other obstacles to care can benefit as well.

At PAF, our passion is to design, implement, and evaluate direct patient services that improve health equity including patient navigation, direct financial assistance, and patient education and empowerment. Our mission is to improve the lives of the patients we serve in ways that have meaningful and lasting impact.

None of this would be possible without you – the donors who champion our commitment to the mission through your generous support. It is an honor to say thank you on behalf of the patients whose stories and data are represented on the pages of this report.

A handwritten signature in black ink that reads "Alan J. Balch".

Alan J. Balch, PhD
Chief Executive Officer



PAFatwork.org/CEOintroduction

Overall Foundation Impact

Summary of PAF Total Patient Cases and Contacts in 2019

Total Patient Case Count	145,815
Case Management Cases	23,702
Co-Pay Relief Cases	73,007
Financial Aid Fund Cases	42,124
Patient Services Email Helpline Sessions	6,982

Total Patients Served by PAF Between 1996 and 2019 **1,364,370**

619

DISTINCT PATIENT DIAGNOSES
increased by **6%** over 2018

238

DISTINCT RARE DISEASES
increased by **7%** over 2018

The Programs Through Which We Deliver Direct Assistance

CASE MANAGEMENT

27

total unique programs

- 15** serve patients living with non-cancer diagnosis
- 12** serve patients living with cancer

FINANCIAL SERVICES

11

total unique programs serving patients through many different disease-specific funds

- 50** open disease funds serve patients
- 19** funds serve patients living with non-cancer diagnosis
- 31** funds serve patients living with a cancer diagnosis
- 4** programs are fully administered by PAF for other non-profit organizations

What Our Patients Are Saying...

Patient satisfaction rates were high across all patient programming. Patients and their caregivers felt PAF was helpful, knowledgeable, compassionate and well-informed on issues of importance to them.

Overall Satisfaction Rating (All PAF Programs)

8.97/10

Patient Ratings for PAF Service

4.74/5 | Knowledge of Staff

4.74/5 | Professionalism of Staff

95%

indicated their issues were resolved and/or PAF provided valuable help

96%

would recommend PAF to others

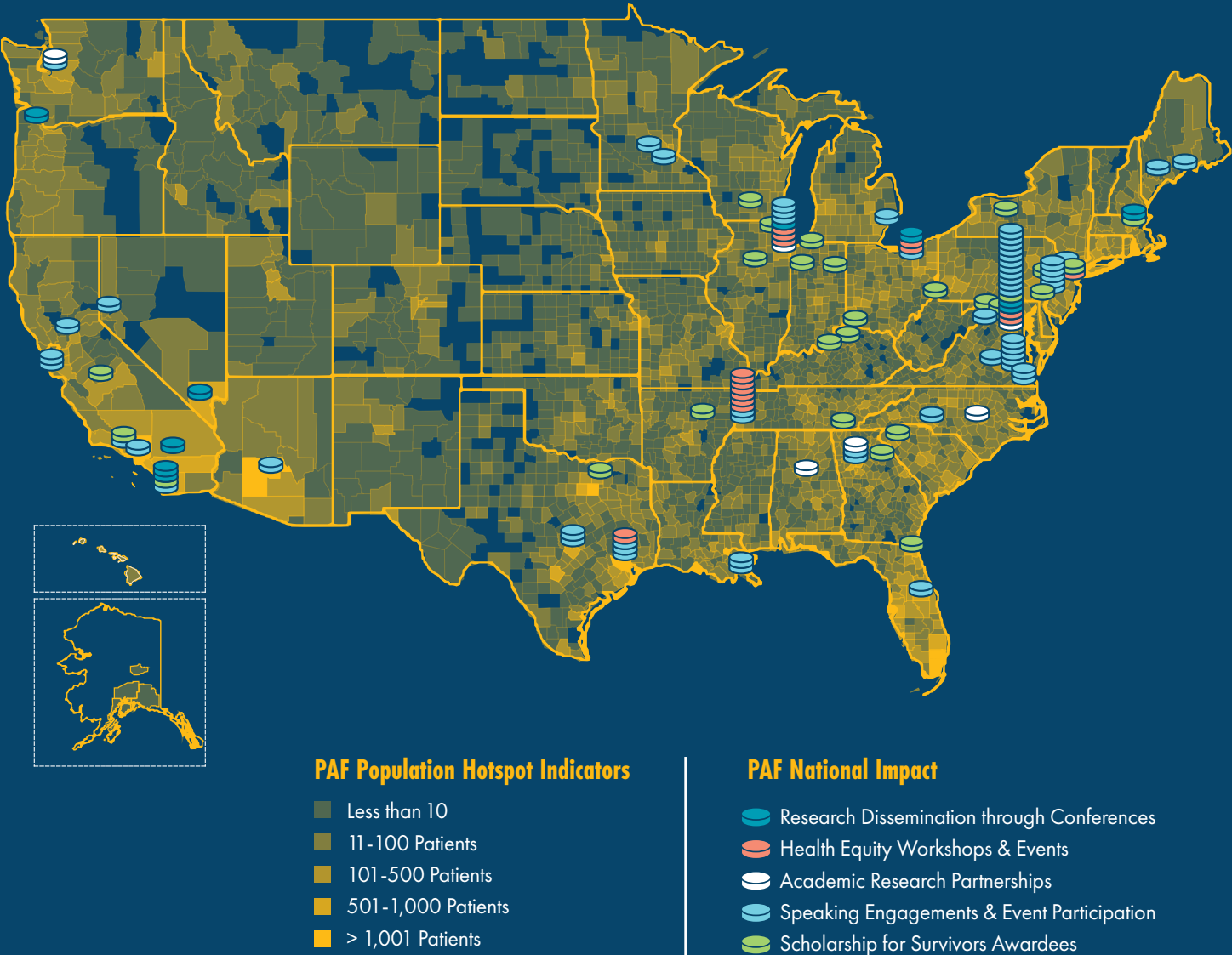
% of Respondents That Would Recommend PAF to Others by Program



Service to All 50 States

PAF served patients in all 50 states and the U.S. territories in 2019. We also engaged in a variety of outreach, education, speaking engagements and event participation across the country. Using county-based data, the map below represents the locations of patients we served and provides insight into specific locations of our on-the-ground activities.

Part of the map is shaded by county to depict the number of patients served by PAF in that county while each chip represents a specific location where PAF was engaged through various activities.



Case Management

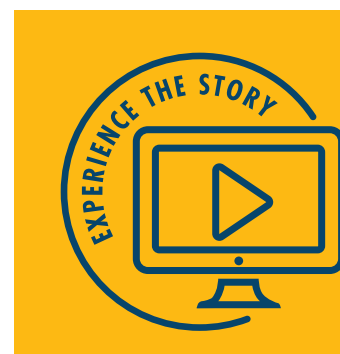
At the heart of our mission is the delivery of effective, compassionate case management interventions to patients who have been diagnosed with a chronic, life-threatening and/or debilitating illness. Through PAF's extensive experience serving patients through case management, more than 24,000 in 2019, we recognize the critical importance of providing sustained assistance to patients wherever they are in their treatment journey today. Many vulnerable and low-income patients need intensive case management assistance at times of personal and financial crises in order to help them achieve their goals of care, improve their health outcomes, adhere to therapy or avoid insolvency.

One-on-one case management is particularly important for disadvantaged patient populations, including disabled, rural, low literacy, low SES patients, and racial and ethnic minorities. Of case management patients, 23% report being disabled, 48% earn \$23,999 or less annually, and 38% are non-Caucasian, with 19% identifying as African American and 12% as Hispanic/Latino.

PAF case managers also seek to mitigate the negative effects out-of-pocket healthcare and cost-of-living expenses have on patients and their families by facilitating access to safety net programs, negotiating resolutions to medical debt and educating individuals on relevant resources. In 2019, these efforts resulted in \$24,228,692 in debt relief obtained on behalf of patients.

Of the 27 programs offered through the case management division, **9 were new**, including the Sickle Call CareLine, ALS Medicare Resource Line, Migraine Matters Case Management and the Personalized Medicine CareLine.

The majority of patients and caregivers who reach out to PAF's case managers do so at the recommendation of other disease-specific patient advocacy groups. In fact, PAF had formal collaborative agreements with ten different non-profit charities in 2019 and for two of those PAF served, and continues to serve, as the administrator of their navigation services.



PAFatwork.org/costofcare

23%

**OF CASE MANAGEMENT
PATIENTS**
report being disabled

48%

**OF CASE MANAGEMENT
PATIENTS**
earn \$23,999 or less
annually

\$24M+

IN DEBT RELIEF
obtained on behalf
of patients

Justin | Colorectal Cancer

“...I was facing loss of insurance as well as high medical bills. As a family we didn't know the best way to manage the bills that were coming in and how the appeal system worked when a service was denied. When I called [PAF], I was only expecting someone to help me by telling me what direction to go. What I got was extraordinary service, compassion, understanding and support. [My case manager] began working on my case immediately. She included me in the phone calls with the hospital accounts payable and [my insurer]. Cancer is a horrible diagnosis and the financial and personal consequences are unbelievable. There are no words to express how grateful we are to PAF and especially to my case manager.”

APPLICABLE RESOURCES & PROGRAMS:

PAF case management interventions are frequently sought out by patients experiencing complex healthcare barriers that are often exacerbated by other factors, including urgent clinical necessity, access to specialized care available only in select locations and the need to facilitate expedient collaboration between multiple stakeholders in order to reach resolution.

23%

CASE MANAGEMENT CASES

involved 3 or more individual issues

- These cases required an average of 21 case management activities to resolve

9%

CASE MANAGEMENT CASES

involved 4 or more individual issues

- These cases required an average of 23 case management activities to resolve

PAF operates numerous case management programs to address the needs of specific diseases.

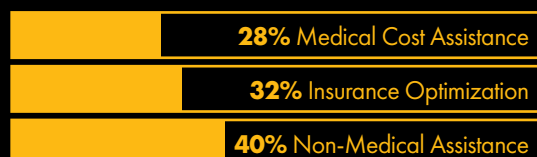
patientadvocate.org/connect-with-services/case-management-services-and-medcarelines/

MEDCARE *Line*
Access to Emerging Medication Therapies



FINANCIAL IMPACT

While PAF case managers do not provide direct financial assistance to callers, their efforts result in financial relief to the patients they serve. This financial impact is measured by the assistance acquired and/or the costs offset by helping callers navigate the medical and insurance systems and connecting callers to appropriate resources.



\$6,574

Average amount recovered through case management interventions for patients who had an issue associated with debt relief

WHEN PAF PATIENTS WERE ASKED...

33%

OF PATIENTS

stated that changes to their employment status led to a loss or "break" in their insurance coverage

55%

OF PATIENTS

indicated their level of financial stress was "overwhelming" or "above average"

32%

OF PATIENTS

stated that out-of-pocket costs for different treatment options were a major factor in treatment decision

2019 DATA POINTS:

Top 3 Case Management Issue Categories:

46%	Insurance Issues
29%	Debt Crisis/Cost of Living
11%	Uninsured Issues

Average amount of financial relief provided by case management
\$989 per case

Financial Services



\$215M+

CPR grant payments
to patients in need

CO-PAY RELIEF

PAF's Co-Pay Relief (CPR) program exists to help reduce the financial distress low-income patients and their families experience when faced with various costs. The program provides direct financial assistance to qualified patients with co-payments, co-insurance or cost-sharing through funds dedicated to specific disease states. **Launched in 2004**, CPR operates in compliance with the guidance provided by the Office of Inspector General (OIG) while delivering **best-in-class** service.

More than **73,000 patients were approved** for assistance in 2019 and served through a total of 38 open disease funds, with grant payments totaling \$215,132,046. PAF knows from decades of experience that low-income patients require extra financial help when it comes to paying for the numerous out-of-pocket costs associated with various diseases.



Patient Advocate Foundation
CO-PAY RELIEF
DISPENSING HELP, DELIVERING HOPE



Barriers to Access and Adherence

9 of 10

PAF patients report that medical costs affect their ability to access and/or adhere to recommended treatment

FINANCIAL ASSISTANCE FUNDS

PAF's **financial aid funds award small grants** to eligible low-income patients to provide for a broad range of practical support needs that can impede a patient's ability to achieve goals of care. These programs are designed to reduce the burden of certain non-medical expenses, including transportation, housing, short-term lodging, utilities and nutritional needs.

SMALL GRANTS REDUCE BURDEN OF



Transportation



Housing



Short-term Lodging



Utilities & Nutritional Needs



42,000

patients served through all
financial assistance funds

Patient Education & Empowerment

Extending the impact of PAF's one-on-one services, our education and empowerment initiatives deliver actionable guidance and expert advice on practical healthcare issues in a variety of formats. The portfolio offers relevant healthcare information and education for all audiences, including patients, caregivers, healthcare professionals and those that are currently healthy.

PAF **released 29 new educational content pieces in Spanish and English, distributed 54,747 PAF publications** and achieved a 9% increase in total searches completed by users of the National Financial Resource Directory over 2018. patientadvocate.org/explore-our-resources/national-financial-resource-directory/

More than 20 expert webcasts are available through PAF's **on-demand Patient Empowerment Series** with new titles including Disability Benefits, Preparing for Open Enrollment and Medicare Open Enrollment Basics. patientadvocate.org/explore-our-resources/webcasts/

“I can take what I learned today and share with others who might be interested in exploring a clinical trial.” – Ann

PAF's **online subscriber community** grew by 19%, with more than 3,400 members by the end of 2019 and engagement rates increasing by 13% over 2018. Community subscribers can choose to receive timely updates from three topic areas: PAF and CPR news, resources and disease-specific information and/or public health news. patientadvocate.org/get-involved/sign-up/



2019 Data Highlights of PAF's Online Subscriber Community Engagement

19%

subscriber list growth over 2018

13%

increase in subscriber engagement rates compared to 2018

24%

PAF-specific subscriber open rate increased from 21% in 2018

> Continued on Pg. 12

Working alongside advocates and medical experts from Migraine, Headache and Neurology fields to identify the topics and resources needed most, **PAF developed Migraine Matters**, an online educational resource tool designed to serve patients with headache and migraine disorders. This resource received almost 30,000 page views in 2019.
migrainematters.patientadvocate.org/



Created by combining the best resources from top nonprofits and clinical experts in the field of cardiovascular treatment and research, **Matters of the Heart is a self-directed online education tool** that features an ever-expanding collection of articles, videos, webinars and infographics, resource directory and guided chatbot designed to provide relevant information to those seeking assistance or education on the unique challenges associated with cardiovascular diagnoses.
patientadvocate.org/matters-of-the-heart/



“There is no greater honor than to meet a patient during the toughest point in their life, and know that my work on their behalf eased their burden and lifted roadblocks that felt insurmountable before we connected.”

– **Courtney Jones**
Senior Director of Case Management



Matters of the Heart 2019 Utilization Statistics





Chicago Convening Think Tank Community Conversation on Breast Cancer with PAF's Shonta Chambers (far right)


Health Equity & Community Engagement

PAF's health equity work is uniquely designed to reach people where they live, work, play and pray. We meet people in communities, within worksites, and other venues that are most comfortable and most convenient for them. These efforts include community engagement and outreach initiatives and the SelfMade Health Network, a national network supported by the CDC Office on Smoking and Health and Division of Cancer Prevention and Control.


From convening **community conversations on breast cancer on Chicago's southside** to facilitating partnerships between health systems and small businesses to **reduce late stage breast cancer diagnosis in Memphis**, and making the "business case" for **lung cancer screening in West Virginia**, PAF's health equity work across the country links limited resource and vulnerable communities to a variety of services that support and assist them.




PAF Health Equity Staff Accomplishments




Participated in
12
outreach events reaching over
2,500
patients, community navigators, caregivers and advocates




Facilitated **2** strategic community conversations on cancer



Convened **3** community focus groups on health insurance literacy



Contributions made by members of PAF's SelfMade Health Network (SMHN) were published in the Journal of Women's Health, titled, *Using Inside Knowledge Campaign Materials to Improve Gynecologic Cancer Knowledge in Underserved Women.*



Educated healthcare providers serving populations with low socio-economic status on the HPV vaccinations in partnership with the National Area Health Education Center Organization

Arthur | Aortic Valve Disorder

“Haven’t had the surgery yet, but many trips to doctors and testing to get my heart ready for surgery... gas and finding rides to and back to see my doctors has been a heavy burden and stressful. Money is so tight it does have an impact on my health. I do have insurance to cover my medical bills, it’s just hard to come up with fuel money and pay someone to take us over for the 100-mile round-trip visits and testing. And motel money for when I have very early testing and night of surgery for my wife and a driver. So, the impact on our life is the financial help from PAF. Thank you.”

APPLICABLE RESOURCES & PROGRAMS:

Our Financial Aid Funds provide small grants to eligible patients for a broad range of support needs and **ease the burden of certain non-medical expenses**, including transportation, housing, short-term lodging, utilities and nutritional needs. patientadvocate.org/connect-with-services/financial-aid-funds

\$600

PAF’s Heart Valve Financial Aid Fund grant increased from \$500 to help with additional expenses now covered by the grant, which includes lodging and transportation



100%

PATIENTS SURVEYED
would recommend a PAF Financial Aid Fund to others

Case management services were added to the Matters of the Heart online tool, ensuring that patients with cardiac conditions who have needs beyond the online resource can now access a case manager for help.

cardio.patientadvocate.org



Matters of the Heart

Working together for health...because it matters

WHEN PAF PATIENTS WERE ASKED...

16%
OF PATIENTS

indicated that they were "very concerned" about transportation to treatment or care during their treatment journey

63%
OF PATIENTS

indicated that "avoiding extreme financial distress" was a personal goal related to their care

59%
OF PATIENTS

stated that the help they received from PAF was "extremely helpful" in aiding them in achieving their care goals

2019 DATA POINTS:

Patients with cardiovascular conditions seeking support from PAF increased by **6%** in 2019

Average Mileage Traveled Each Way for Treatment

26MI All Case Management Cases

47MI Case Management Cases with a Travel Issue

Average miles traveled each way by patients with a Travel Issue increased by **28%** in 2019
(47 miles in 2019 - 37 miles in 2018)

TOP CASE MANAGEMENT ISSUE

Transportation remains one of the top 5 case management issues



7%
OF PATIENTS

State inability to afford transportation expenses is an issue

Service by The Numbers

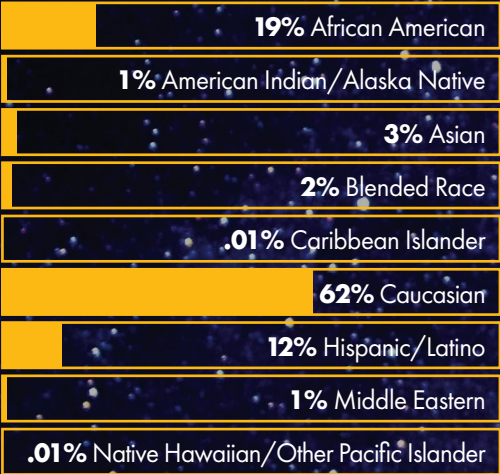
CASE MANAGEMENT

23,702
TOTAL CASE COUNT

387,508
TOTAL CASE CONTACTS

2019
619
DIAGNOSES

ETHNICITY



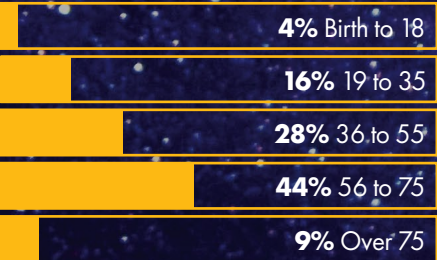
INSURANCE STATUS



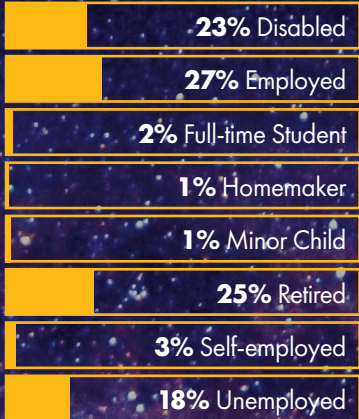
INCOME



AGE



EMPLOYMENT



TOP 5 DIAGNOSIS CATEGORIES & INDIVIDUAL DISEASE BREAKOUT

Cancers 61%

- Breast Cancer
- Prostate Cancer
- Colorectal Cancer
- Lung Cancer
- Non-Hodgkin's Lymphoma

Autoimmune Diseases 2%

- Rheumatoid Arthritis
- Arthritis
- Lupus
- Osteoarthritis
- Psoriatic Arthritis

Cardiovascular Conditions 6%

- Pulmonary Hypertension
- Hypertension
- Congestive Heart Failure
- Heart Attack
- Atrial Fibrillation

Chronic or Debilitating Conditions 10%

- HIV, AIDS
- Osteoporosis
- Crohn's Disease
- COPD (Lung Disease)
- Hepatitis B

Nervous System Conditions 5%

- Multiple Sclerosis
- Stroke (CVA)
- Parkinson's Disease
- Epilepsy
- Migraine

TOP 5 SPECIFIC CASE MANAGEMENT ISSUES REPORTED



10%

Inability to afford care - hospital/facility cost share



9%

Inability to afford care - medication cost share



7%

Inability to afford transportation expenses



7%

Inability to afford rent/mortgage



6%

Inability to afford utility/shut off notice

TOP 15 CASE MANAGEMENT RESOLUTIONS

14%	Obtained financial assistance- negotiated payment plan/discount
8%	Facilitated/secured free or charity for transportation assistance
7%	Facilitated rental/mortgage payment relief
6%	Facilitated utility/phone relief
6%	Applied for financial assistance
6%	Educated on general benefits & coverage
4%	Guidance provided regarding disability process
3%	Offset cost through alternative assistance
3%	Facilitated/located food assistance
2%	Enrolled into pharmaceutical indigent drug program
2%	Facilitated access to care through local clinic/hospital/doctor
2%	Facilitated/identified new insurance coverage
2%	Facilitated application for financial assistance - premium assistance
1%	Provided guidance regarding the Affordable Care Act (ACA)
1%	Approved for financial assistance

TOP 10 DIAGNOSES FOR CASE MANAGEMENT



Breast Cancer



Prostate Cancer



Colorectal Cancer



Lung Cancer



Non-Hodgkin's Lymphoma



Multiple Sclerosis



Leukemia



Multiple Myeloma



Testicular Cancer



Ovarian Cancer



Patient Advocate Foundation

CO-PAY RELIEF

DISPENSING HELP. DELIVERING HOPE



73,007

Patients Approved



7

Average Contacts per Case



\$215,132,046

Grant Payment Totals



242,845

Incoming Calls Handled



705,540

Total # of Grant Payments

Total Patients Served by CPR Since Inception

450,421

6 NEW CPR DISEASE FUNDS LAUNCHED IN 2019

- Cystic Fibrosis
- Pulmonary Fibrosis
- Rheumatoid Arthritis
- Skin Cancer
- Ulcerative Colitis
- Uterine Cancers

Tameka | Colorectal Cancer

“I would have never known about any of the programs that were available to me. There was so much information that a person not in the healthcare system wouldn't know to look for. My case manager was amazing. She would even call sometimes just to check on me and be sure I was in good spirits. For me that meant a ton. She made so many calls and did so much searching on my behalf I felt like family to her. I'll never forget her!”

APPLICABLE RESOURCES & PROGRAMS:

The **National Financial Resource Directory** is an online educational tool that provides patients with an immediate, comprehensive list of customized state, local and national resources based on their unique search criteria.

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



1,125,846

RESOURCES

matched to users' needs



36,782

COMPLETED SEARCHES

9% increase over 2018

PAF launched **9 new case management programs** in 2019 including the **Cancer Navigation Demonstration Program**, in collaboration with the Florida Alliance for Healthcare Value, that is designed to evaluate the effectiveness of proactive and reactive navigation as an intervention for cancer patients. The program measures the reduction in financial and emotional stress, time away from work and access to and utilization of employer-based benefits. PAF provides proactive benefit education and navigation to each employee and/or dependent contacting the program and delivers reactive case management services to resolve emergent access and affordability issues.

WHEN PAF PATIENTS WERE ASKED...

66%
OF PATIENTS

reported that receiving case management services from PAF reduced their stress

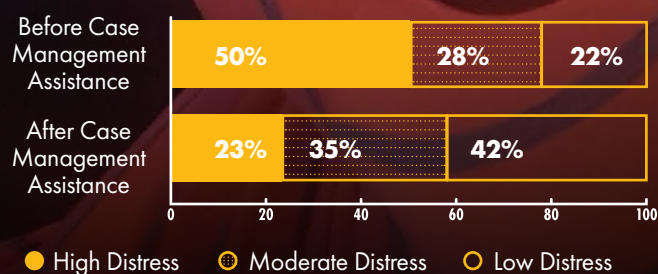
92%
OF PATIENTS

served by PAF's case management team would recommend our organization to others

20%
OF PATIENTS

served by PAF used our online educational publications or website resources

PATIENT DISTRESS LEVELS

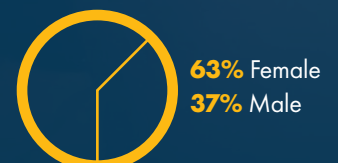


2019 DATA POINTS:

Average number of contacts per case management case: **16**

Case management patients were younger in 2019 – 20% were 35 or younger – an increase of **15%** over 2018

Case management Gender:



Advancing the Science of Patient Navigation

Knowing a patient’s priorities and financial stressors while coping with a chronic, life-threatening and/or debilitating illness is not enough. We must also align the support and resources necessary to assist them in addressing their concerns and minimizing cost. While the concept of patient navigation has been recognized as an important aspect of providing quality care for some time, financial navigation has emerged as an area of heightened interest due to the impact of medical debt and material hardships on patients and families.

Data Collection Activities

To ensure that PAF’s research projects reflect what matters most to our patients, PAF conducted 2 large retrospective survey projects and 3 prospective micro surveys targeting issues or concerns that were observed in current quantitative and qualitative data from our patient population.

RETROSPECTIVE SURVEYS

Cross-sectional retrospective studies allow PAF to formulate hypotheses about possible associations between an outcome of interest and patient demographics and enable us to investigate potential relationships after help is delivered.

>6,200
PATIENTS

participated in retrospective
survey projects
24% response rate

PROSPECTIVE MICRO SURVEYS

To capture patient perspectives prior to service delivery, data collection fields were embedded into Co-Pay Relief’s online portal workflow to facilitate rapid research and evaluation initiatives.

>3,250
PATIENTS

participated in micro
survey projects

Research Dissemination

Dissemination is an important component of the research process, and the utilization of PAF’s research findings is an organizational priority.

7 abstracts accepted and
presented at national conferences.
(5 posters, 2 oral presentations)

1 blog post

2 peer-reviewed journal articles

Published Articles in Collaboration with Research Partners

Fred Hutchinson Cancer
Research Center
Pilot Feasibility Study
of an Oncology Financial
Navigation Program
Journal of Oncology Practice

Emory University/ECOG-ACRIN
Pilot Feasibility Study of an
Oncology Financial Navigation
Program in Brain Cancer Patients
American College of Radiology

ADAP AAA+
Navigating the Costs of HIV Care
– Conversations, Resources
& Patient Experience
Online Blog

KEY FINDINGS FROM 2019 PAF SURVEY PROJECTS

 Quality of Life	29% of patients rate their physical health as "excellent" or "very good"	31% had a general distress score greater than 7 in the past 7 days (10 point scale)	17% had a discussion with their physician about palliative care	1 in 3 were very concerned about returning to daily activities	48% stated that maintaining current quality of life was a personal care goal
 Care Conversations	1 in 4 patients were "very concerned" about having enough information about treatment options	65% stated doctor listened carefully to them	57% shared personal goals related to care with doctor	43% had complete trust in their doctor or medical provider	2 in 3 stated that their doctor explained things in a way that was easy to understand
 Barriers to Care	58% said that cost of deductibles, copay or coinsurance impacted care	34% said challenges with insurance coverage impacted ability to achieve care goals	12% stated transportation cost as a barrier to care	1 in 10 said unemployed status led them to avoid medical care after diagnosis	63% experienced financial hardship due to the cost of medical care
 Treatment Decision Making	32% stated that out-of-pocket costs were a major factor when selecting a treatment option after diagnosis	35% of employed patients went on paid disability due to their diagnosis or treatment	1 in 2 expressed a confidence level of "10" when asked about taking an active role in making care decisions	47% patients were "very concerned" about the long-term side effects of their treatment choice	72% said work impact was "extremely" or "very" important to discuss when making care decisions
 Financial Impact	55% took a significant amount of time away from work for treatment	1 in 5 felt an overwhelming level of financial distress	15.8 average cost score of patients served by PAF in 2018 (0-44 lower score indicates greater financial toxicity)	3 in 4 were very concerned about the overall financial cost of treatment	43% said that day-to-day living expenses were their largest unmet need

RESEARCH PARTNERS

In 2019, PAF further expanded our collaborative research partnerships with other academic and non-profit organizations.

ORGANIZATION	PROJECT	LOCATION
Fred Hutchinson Cancer Research Center	Safeway Financial Navigation Program	Seattle, WA
LUNGeVity Foundation	Treatment Preferences of Lung Cancer Patients and Caregivers	Chicago, IL
University of Alabama at Birmingham	Quantifying Breast Cancer Patient Preferences and their Association with Financial Toxicity during Treatment Decision-making	Birmingham, AL
Emory University/ECOG ACRIN Cancer Research Group	Measuring Outcomes of Financial Counseling in Brain Cancer Study	Atlanta, GA
University of North Carolina at Chapel Hill	Improving the Reach and Quality of Cancer Care in Rural Populations	Chapel Hill, NC
National Institutes of Health Center for Genomic Research	The Case-Manager Experience: Evaluating Underserved Populations' Access to Genomic Medicine and Clinical Trials	Washington, DC

PROGRAM EVALUATION

PAF routinely engages in program evaluation, using this standardized tool to strengthen quality and improve outcomes. The results are used to evaluate the quality and effectiveness of our programs. Internal projects are focused on our case management population in the areas of Patient Engagement, eHealth Literacy and Employee Satisfaction and Productivity.

Data highlights from 2019 research and evaluation projects are presented throughout the report.



CEO Alan Balch welcomes Connor Newsom, PAF scholarship recipient, who shared his inspiring journey from cancer diagnosis to successful college student.



Guests took part in 225 silent auctions totaling over \$30,000 in market value.



Guests enjoyed dinner, casino games and dancing.

A Promise of Hope Affair

PAF's premiere fundraising gala, the 18th annual A Promise of Hope Affair (POH), was held in February at the Newport News Marriott at City Center in Virginia. This event raised nearly \$145,000 in support of patients served through our case management programs and **\$70,000 in support of students served through our Scholarship for Survivors program.**

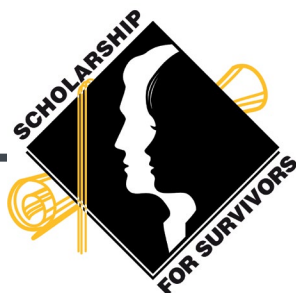
This engaging event drew over 330 guests from across the nation and the local community and was supported by 25 event sponsors. Guests heard from two courageous young students supported by PAF's Scholarship for Survivors program. They also enjoyed dinner, dancing, casino games and a live and silent auction.

To learn more about A Promise of Hope Affair, visit promiseofhope.net

Scholarship for Survivors

Over the past 20 years, the Scholarship for Survivors program has supported 113 deserving college students whose educational pursuits were disrupted due to a chronic illness through **scholarship awards totaling over \$640,000**. PAF, along with many other gracious funders, has enabled 50 of these bright and courageous young adults to realize fully degreed graduation with 25 still pursuing their course of study. Scholarship recipients are eligible to receive \$3,000 per school year for four consecutive years.

Learn more about our scholarship program
patientadvocate.org/scholarships



Congratulations to the new 2019 – 2020 scholarship winners:

Asia Werner | University of Cincinnati, Nursing

Josh Parker | California State University-Fresno, Biology

Adam Ponedal | Northwestern University,
Chemical & Biological Engineering

Leia Hunt | Collin College, Business Management

Nicole Killigrew | Bellarmine University, Nursing

Elena Evans | Georgetown University, Pre-Med

Wesam Kanim | University of California San Diego, Bioengineering

Adam Enomoto | University of California, Los Angeles, Pre-Med

In addition to the eight new awardees the scholarship program will also support 17 returning students this academic year.



“... At the age of 15, I was diagnosed with osteosarcoma ... My left leg was amputated above the knee and part of my right lung was removed. At age of 17, my cancer relapsed in my right hip ... At the age of 19, my cancer relapsed in my right thigh. Now, I am in my 3rd and last year of college to complete my Diagnostic Medical Sonography degree! I was given the chance to make my dreams come true and am truly grateful to those who generously donate to the PAF Scholarship for Survivors program.”

– **McKayla** | scholarship recipient



PAFatwork.org/Sierra



Patient Congress participants

Patient Congress

In September, PAF hosted its 20th annual Patient Congress in Washington DC, an event that brings together patients, caregivers and health professionals from throughout the U.S. to network, learn and educate about what matters most to

seriously ill patients. The 2019 event **focused on cost of care, using stories and advocacy** through several components (education, networking, and a StorySlam) to **advance awareness about healthcare costs.**

To experience the event, visit npaf.org/what-we-do/patient-congress-2019-full/

Breakaway from Cancer & Breakaway from Heart Disease

PAF was pleased to partner again with the Amgen Breakaway from Cancer™ (BFC), and its new component Breakaway from Heart Disease™ (BFHD), whose **main event is the Amgen Tour of California, a seven-stage bike race through California.** This year's race started in Sacramento and ended in Pasadena at the Rose Bowl, with **PAF manning booths at both locations and educating attendees about our services and resources.** Other BFC partners included Prevent Cancer Foundation, Cancer Support Community, National Coalition for Cancer Survivorship, Susan G. Komen and the Multiple Myeloma Research Foundation.

New in 2019 was Amgen's Breakaway Challenge, started on 4/1/19, which joined BFC and BFHD to urge participants to turn their walking, running or cycling miles into support for the non-profit advocacy partners. Amgen generously donated \$1 for every Breakaway Challenge mile completed by initiative participants.



"I learned how to incorporate my story into larger healthcare conversations. I found courage and renewed hope when I shared my story and listened to others. Collectively, our stories offered a rich perspective of the deficits found within the American healthcare system ... I learned the term "patient centered care" which offered the way to communicate the "how" when having healthcare conversations ... The isolation of caregiving melted away ..."

– **Paula**
Volunteer and Patient Congress participant



PAFatwork.org/caregiverToni

SUMMARY OF TOTAL PATIENT IMPACT IN FISCAL YEAR 2018/19

Total Patient Cases	139,465
Total Case Management Cases	24,627
Total Co-Pay Relief Cases	75,580
Total Financial Support Programs Cases	33,263
Total Patient Services Email Helpline Sessions	5,995
Total Patient Services Case Contacts	1,285,948

SUMMARY OF CASE MANAGEMENT IMPACT IN FISCAL YEAR 2018/19

Total PAF Case Management Case Count	25,525*
Unique Case Management Patient Issues	44,367
Total PAF Case Management Contacts	410,954
Average Contacts per Case	16.1

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

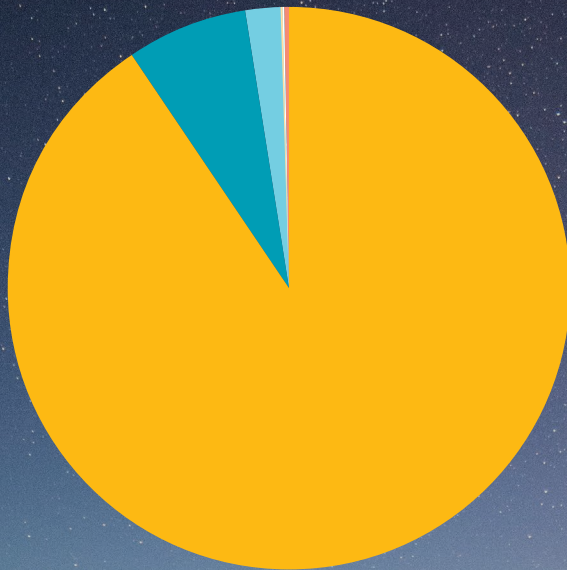


Patient Advocate Foundation Statements of Financial Position June 30, 2019 and 2018

	2019	2018
ASSETS		
Current assets		
General operating cash and cash equivalents	\$ 28,077,632	\$ 24,050,994
Restricted cash and cash equivalents	250,800,565	261,254,275
Unconditional promises to give	17,254,062	30,424,481
Service contract receivable	538,498	514,231
Due from National Patient Advocate Foundation	18,437	7,373
Investments and cash equivalents	2,078,900	1,999,015
Inventories	42,269	58,570
Prepaid expenses	412,217	405,146
Total current assets	299,222,580	318,714,085
Property and equipment, net	4,321,760	4,218,172
Other assets		
Refundable deposits	50,331	50,331
	\$ 303,594,671	\$ 322,982,588
LIABILITIES AND NET ASSETS		
Current liabilities		
Accounts payable and accrued expenses	\$ 3,763,880	\$ 8,650,706
Due to National Patient Advocate Foundation	10,290	29,385
Postretirement benefits liability, current portion	34,233	–
Deferred revenue	16,670,044	18,203,925
Accrued vacation leave	462,147	318,690
Total current liabilities	20,940,594	27,202,706
Long-term liabilities		
Postretirement benefits liability, less current portion	3,137,549	2,422,014
Incurred but not recorded liabilities	126,804	92,974
Total long-term liabilities	3,264,353	2,514,988
Total liabilities	24,204,947	29,717,694
Net assets without donor restrictions		
Undesignated	13,272,753	9,557,450
Board designated	2,078,900	1,999,015
Total net assets without donor restrictions	15,351,653	11,556,465
Net assets with donor restrictions		
Restricted by purpose	264,038,071	281,708,429
Total net assets	279,389,724	293,264,894
Total liabilities and net assets	\$ 303,594,671	\$ 322,982,588

Patient Advocate Foundation Statements of Activities Years Ended June 30, 2019 and 2018

	2019			2018		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
OPERATING REVENUES						
Contributions:						
Grants	\$ 3,759,260	\$ 217,776,219	\$ 221,535,479	\$ 3,138,681	\$ 352,845,740	\$ 355,984,421
Private and public donations	165,787	-	165,787	158,632	-	158,632
Donated services and materials	35,314	-	35,314	40,374	-	40,374
Program administration	16,996,013	-	16,996,013	19,172,394	-	19,172,394
Patient Congress	80,000	-	80,000	10,000	-	10,000
Promise of Hope	141,650	-	141,650	149,858	-	149,858
Patient Action Council	75,000	-	75,000	150,000	-	150,000
Investment return	5,559,850	-	5,559,850	2,919,767	-	2,919,767
Net assets released from restrictions:						
Satisfaction of program restrictions	235,446,577	(235,446,577)	-	271,049,655	(271,049,655)	-
Total revenues, gains and other support	262,259,451	(17,670,358)	244,589,093	296,789,361	81,796,085	378,585,446
OPERATING EXPENSES						
Program services:						
Patient/educational services	5,867,102	-	5,867,102	4,931,805	-	4,931,805
Financial aid programs	242,788,385	-	242,788,385	278,416,531	-	278,416,531
Service contracts	5,234,955	-	5,234,955	5,268,447	-	5,268,447
Supporting services:						
Management and general	2,746,021	-	2,746,021	2,700,616	-	2,700,616
Fundraising	1,138,723	-	1,138,723	1,079,528	-	1,079,528
Total expenses	257,775,186	-	257,775,186	292,396,927	-	292,396,927
Change in net assets from operations	4,484,265	(17,670,358)	(13,186,093)	4,392,434	81,796,085	86,188,519
OTHER NONOPERATING CHANGES						
Postretirement benefit charges other than periodic cost	(689,077)	-	(689,077)	(255,504)	-	(255,504)
Change in net assets	3,795,188	(17,670,358)	(13,875,170)	4,136,930	81,796,085	85,933,015
Net assets, beginning of year	11,556,465	281,708,429	293,264,894	7,419,535	199,912,344	207,331,879
Net assets, end of year	\$ 15,351,653	\$ 264,038,071	\$ 279,389,724	\$ 11,556,465	\$ 281,708,429	\$ 293,264,894



COMBINED REVENUES

- **91%** Program Grants – \$221,535,479
- **7%** Program Administration – \$16,996,013
- **2%** Interest – \$5,559,850
- **.10%** Gifts & Contributions – \$240,787
- **.09%** Event Revenue – \$221,650
- **.01%** In-Kind Service – \$35,314

TOTAL \$244,589,093

COMBINED FUNCTIONAL EXPENSES

- **98%** Program Services – \$253,890,442
- **1%** Management & General – \$2,746,021
- **.44%** Fundraising – \$1,138,723

TOTAL \$257,775,186



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PAF gives back to our community by supporting local charities and events



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