25 years of delivering PATIENT ADVOCACY by supporting patient journeys
Welcome

Patient Advocate Foundation (PAF) has provided direct assistance over the past 25 years to more than 1.5 million seriously ill patients who are in a moment of crisis. As our nation is poised to emerge from the COVID-19 crisis, I can say proudly that we at PAF are undaunted in our commitment to addressing the unique needs of vulnerable patients and families struggling to access quality healthcare services and overcome the financial ravages of illness.

The communities we serve have long endured unequal access to care and the challenges created by the many social determinants of health. The pandemic has drawn much-needed public awareness of these inequities while also intensifying the need for the work we do at the individual and community level. Our mission has never been more motivating and our dedication more important to finding solutions for patient populations facing barriers related to necessities like food, housing, transportation and insurance coverage.

You will see in this report the impact of our programs that brought direct relief to nearly 193,000 patients in 2020. More importantly, you will get to know the people who make us what we are – the patients and caregivers we serve along with our dedicated staff and partners who roll up their sleeves to help.

You will also see our values, which have long been grounded in a belief that each member of the community should have equal opportunity to achieve good health. This core principle is reflected in the practical problems we address and the specific populations we serve through case management, financial assistance, education and training, health services research and community outreach.

PAF will continue to help one patient at a time and one community at a time thanks to your sustained support. On behalf of the patients and families we are privileged to serve, I offer my deepest gratitude to those who make our work possible and invite you to continue the journey with us.

Alan J. Balch, PhD
Chief Executive Officer

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 2020, and we’ve helped a cumulative total of more than 1.5 million patients nationwide with support provided by more than 200 staff.
### Overall Foundation Impact

**Summary of PAF Total Patient Cases and Contacts in 2020**

<table>
<thead>
<tr>
<th>Total Patient Case Count</th>
<th>192,881</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Management Cases</td>
<td>21,161</td>
</tr>
<tr>
<td>Co-Pay Relief Recipients</td>
<td>71,115</td>
</tr>
<tr>
<td>Financial Aid Fund Recipients</td>
<td>61,197</td>
</tr>
<tr>
<td>PAF COVID Financial Support Recipients</td>
<td>23,866</td>
</tr>
<tr>
<td>Patient Services Email Helpline Sessions</td>
<td>15,542</td>
</tr>
</tbody>
</table>

**Total Patients Served by PAF Between 1996 and 2020**

1,556,713

**Diagnoses Served by PAF**

- **629** distinct patient diagnoses
- **246** distinct rare diseases

**The Programs Through Which We Deliver Direct Assistance**

**Case Management**

- 31 total unique programs
  - 16 serve patients living with a diagnosis other than cancer
  - 15 serve patients living with cancer
  - 4 programs fully administered by PAF for other non-profit organizations

**Financial Services**

- 16 patient assistance programs provide financial support to patients across 92 unique funds
- 59 disease funds assist with medication costs
- 20 funds provide travel assistance to patients
- 8 funds provide cost-of-living assistance to patients
- 5 funds provided financial assistance to people impacted by COVID-19

**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. The overall survey completion rate of 5%, results reflect high rates of satisfaction across all patient programming, with patients and their caregivers reporting that PAF was helpful, knowledgeable, compassionate and well-informed on issues of importance to them.

**2020 Overall Patient Satisfaction Rating**

**9.7 of 10**

**Patient Ratings for PAF Service**

- 98% indicated their issues were resolved and/or PAF provided valuable help
- 99% would recommend PAF to others

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

- **95%** Case Management
- **99%** Co-Pay Relief
- **99%** Financial Aid Funds

### Service to All 50 States

PAF served patients in all 50 states and the U.S. territories in 2020. Using county-based data, the map below represents the locations of patients we served and provides insight into the number and type of engagement activities in specific locations. Shading by county depicts population density of PAF patients. Chips represent a specific location for a PAF program, event or activity. The top ten patient service states are outlined in white.

Some in-person conference and event participation took place in early 2020; however, the onset of COVID-19 required a pivot to innovative, virtual participation formats. This successful transition provided PAF with access to larger, new, more diverse and non-traditional audiences.

### Overall Foundation Impact

**PAF Population Hotspot Indicators**

- Research Dissemination through Conferences
- Health Equity Workshops & Events
- Academic Research Partners & Stakeholders
- Speaking Engagements & Event Participation
- Scholarship for Survivors Award Recipients

**PAF National Impact**

- **Increased by 32% over 2019**
- **Top 10 Patient Service States**
  - Florida: 12%
  - Georgia: 10%
  - Texas: 8%
  - California: 6%
  - New York: 5%
  - North Carolina: 5%
  - Alabama: 5%
  - South Carolina: 5%
  - Ohio: 4%
  - Illinois: 4%
COVID-19 Response

PAF’s ongoing response to COVID-19 has been shaped by guiding principles that placed the health of our staff and families and the ability to continue providing high-quality service to our patients at the forefront.

Within days of the first state-issued stay-at-home orders, PAF established a COVID-19 Emergency Response Plan and implemented associated activities including:

- **Development of an enterprise-wide Pandemic Response plan**
- **Development of a Remote Desk Services plan**
- **Successful transition of 96% of PAF staff to a work-from-home model, with no interruptions to service availability for our patients**
- **Development and implementation of flexible framework for PAF parents of school-aged children in remote learning models**
- **ExpandedFMLA protections for our staff**

PAF focused on the urgent, unmet needs facing patients and their families that resulted from COVID-19 and the wide-spread restrictions designed to mitigate the spread of the virus. PAF worked with new and existing partners to develop and deliver easily accessible, impactful direct assistance and educational initiatives for those patients and families suffering from the virus and its impacts. These efforts resulted in valuable resources, including:

- **COVID Care Resource Center**
  - patientsadvocate.org/covidcare/
  - COVID Care Webinar Series
  - COVID Care Resource Directory
- **COVID Care**
  - case management support program
  - 1-800-532-5274
- **PAF’s Co-Pay Relief Program COVID-19 Fund**
  - copays.org/funds/covid-19/
- **COVID Care Recovery Fund**
  - serving patients through November 3, 2020
- **COVID-19 Emergency Food Assistance Program**
  - In partnership with Team Rubicon and Bristol Myers Squibb Foundation

PAF has been privileged to serve alongside so many others in 2020 to deliver responsive, efficient, compassionate interventions that overcome healthcare access obstacles and bring financial relief to patients and families in need. Our resolve to maintain these safety net resources for those impacted by the pandemic remains intact as we continue to band together as a nation to eradicate COVID-19.
Providing effective, compassionate case management interventions to patients diagnosed with a chronic, life-threatening and/or debilitating illness has always been at the heart of our mission, and 2020 brought urgent challenges to the patients and families we serve. Many patients were in crisis and turned to PAF for help with the most basic necessities, such as food, housing and medical bills. Our team of case managers responded, delivering comprehensive help to more than 21,000 patients across the country, with an emphasis on reducing emotional distress and improving health outcomes.

Connection with personalized case management is particularly important for specific populations that experience premature mortality because of their most critical social determinants of health, or, more specifically, the gaps caused by them. These include disabled (22% of case management patients report being disabled), rural, low literacy, limited resource patients (47% of case management patients earn $23,999 or less annually), and racial and ethnic minorities (45% of our patients were non-Caucasian with 28% identifying as African American and 11% as Hispanic/Latino).

Our case managers are often called to help with the negative effects 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 options for healthcare coverage and relevant resources. In 2020, these efforts resulted in $25,302,209 in debt relief secured on behalf of patients.

Of the 31 case management programs, 6 were new, including COVID Care, the Cancer Navigation Program and four financial navigation studies in partnership with health service researchers at academic cancer centers.

Eleven of our case management programs are fully funded by donations and grants from non-profit organizations. For example, PAF administers the Livestrong Navigation and Fertility Discount programs, which assisted 3,440 clients in 2020, as well as ZERO: The End of Prostate Cancer’s ZERO360: Comprehensive Patient Support Program. Our partnership with ZERO expanded this year with the launch of the ZERO Drive Program. These highly-valued collaborations bring together organizational strengths, expanding the reach and scope of impactful interventions for patients in need.

Many patients require extra financial help with paying for the numerous out-of-pocket healthcare costs associated with a diagnosis. PAF’s Co-Pay Relief (CPR) program exists to help reduce the financial distress low-income patients experience when faced with various costs. The program provides direct financial assistance for co-payments, co-insurance or cost-sharing to qualified patients 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 with an emphasis on ease of access and high-quality patient service.

More than 71,000 patients were approved for assistance in 2020 and served through a total of 41 open disease funds, with grant payments totaling $250,070,049.

PAF’s financial aid funds award small grants to eligible low-income patients for a broad range of non-medical expenses including food, transportation, housing, short-term lodging and utilities. The economic impact of COVID-19 financially devastated millions of households and threatened access to the most basic necessities, making the availability of the safety net support offered by these programs even more critical for the survival and recovery of patients and their families.

PAF also partners with non-profit organizations to manage the administration of their financial assistance programs. In 2020, PAF’s financial call counselors delivered assistance to 85,063 patients, a 102% increase over 2019. These funds successfully processed more than 256,000 individual grant payments to patients in need.
While PAF’s case management program does not provide direct financial assistance to callers, case managers often help find financial relief for patients when needed.

$25M+
in documented debt relief obtained through case management

29%
of people who called for help from a PAF case manager were calling because of an issue concerning medical bills.
Patient Education & Empowerment

Considering the unprecedented impact of COVID-19 during 2020, it was critical that our education and communication activities quickly pivot to support the overall needs of our patients and partners. Beginning in March, a flurry of multichannel communication tools were developed for and shared with a broad array of stakeholders. These communications included public announcements regarding PAF’s operational response to COVID-19, newly developed resources, partnerships, direct support programs and/or educational opportunities for those impacted by the pandemic.

PAF’s education and empowerment initiatives deliver actionable advice and expert guidance to improve the healthcare consumer experience and empower patients to self-advocacy. Our free, publicly available resources are relevant to all audiences and address a wide array of topics.

The Education Resource Library contains PAF’s entire catalogue of content in an easily accessible, searchable format, crossing category filters for 12 topics, 4 content types and 2 languages. In 2020, 7 new, 32 updated and 9 translated publications were released, along with 28 webinars. A video introduction helps new users find the answers they are looking for.

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

The National Financial Resource Directory (NFRD) is PAF’s most utilized educational tool. It provides users with an immediate list of relevant resources based on their search criteria and offers insights otherwise gained only through one-on-one case management.

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

The COVID Care Resource Center features 315 resources and helped more than 29,000 unique visitors between launch in March and December 31, 2020. In response to the rapid and continual flow of new information related to COVID-19, PAF’s education team performed real-time, ongoing audits to ensure the availability of timely, accurate resources. Modeled after the NFRD (see page 12), our COVID resource center includes 14 categories of assistance programs that offer services or financial aid to individuals affected by the pandemic.

patientadvocate.org/covidcare/resources

Of the 54 educational videos available on-demand, the most viewed titles in 2020 were:

- Federal Government COVID-19 Crisis Response to Support Patients and Families
- Coronavirus 101: Learn from PAF’s Epidemiologist
- 3 Good Ways to Plan for Your COVID-19 Care Right Now

“This was a very informative webinar… thank you again. A TON of information in a short amount of time. Concise and easy to understand” – K. Carter

PAF electronic news messages drawing the highest audience engagement included:

- Are New Year Deductibles Busting Your Budget?
- PAF Deploys a Range of Safety Net Services to Help Patients and Families Impacted By COVID-19
- Team Rubicon and PAF Launch the COVID-19 Food Assistance Program
- Discussing Financial Consequences of Serious Illness
- CPR Opens Pancreatic Cancer Fund
- We Are PAF: Meet Jasmine, Meet Brendan, Meet Rita, Meet Carlette, Meet Courtney, Meet Kayla

Migraine Matters, an online educational resource tool, serves patients with headache disease. In 2020, PAF partnered with the Headache and Migraine Policy Forum and Coalition of Headache and Migraine Patients to expand awareness and utility of the tool, which garnered 43,708 page views, a 47% increase over 2019.

migraine.pafcareline.org

PAF’s new publication Getting the Right Test at the Right Time: A Cancer Patient’s Guide to Biomarkers addresses misperceptions about, and the essential role of biomarker testing in, cancer treatment. Supported by the Solutions to Empower Patients program,

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

Matters of the Heart (MOH). PAF’s self-directed online education tool combines the best resources from top non-profits and clinical experts in cardiovascular care and captures an expanding collection of articles, videos, webinars, resources and guided chatbot. MOH received more than 11,000 page views, a 60% increase over 2019, with more than 5,000 unique visitors, a 74% increase.

patientadvocate.org/matters-of-the-heart

We invite you to subscribe to our electronic news delivery at patientadvocate.org/get-involved/ sign-up
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.

Early on, PAF prioritized the need to reach historically underserved populations through outreach and education initiatives focused on African American, Hispanic/Latino and American Indian/Alaska Native communities. These efforts were supported by a diverse and committed donor base of government agencies, corporate and non-profit partners. In 2002, 12% of patients receiving PAF case management services identified as African American, 4% as Hispanic/Latino and less than 1% as Asian. Thanks to our sustained community outreach over the years, we have been able to dramatically increase and maintain racial and ethnic diversity among the patients served by case management. In 2020, 28% of those receiving case management services identified as African American, 11% as Hispanic/Latino, 3% as Asian and 5% as American Indian/Alaska Native.

Many of PAF’s activities are based on strategic partnerships with other organizations in order to reach racially diverse breast cancer patients, with an additional emphasis on young women. We align with national organizations such as Touch, The Black Breast Cancer Alliance along with the Young Survival Coalition, as well as with local grassroots organizations across Memphis and Chicago supporting African American and/or Hispanic women, including Carolyn and Karen Spiritual Healing House, Resurrection Project- ELLAS (En La Lucha a Sobrevivir), Sister’s Network (Chicago & Memphis Chapter) and ALAS-WINGS. We leverage national social media audiences through our partnership with the LIVE Today Foundation. We joined forces with Tigerlily Foundation at the 2020 American Society for Clinical Oncology (ASCO) Virtual Conference to participate in the 2020 #ListenUpMBC CONFAB on Young Women MBC Disparities to educate young women about resources to support them along their cancer journey.

PAF administers the SelfMade Health Network (SMHN), which is part of the Center for Disease Control’s consortium of national organizations to advance the prevention of commercial tobacco use and cancer in populations experiencing tobacco- and cancer-related disparities. SMHN focuses on the implementation of evidenced-based strategies that address cancer and tobacco-related disparities among populations with low socio-economic characteristics.

In 2020, SMHN’s three webinar trainings (selfmadehealth.org/webcasts/) attracted more than 450 attendees from 31 states, representing voluntary health organizations, worksites, health consortiums, federally qualified health systems and cancer institutes and centers. Titles include:

- Understanding Social Determinants of Health to Advance Cancer Health Equity: Clinical Community-Linkages
- Cancer Survivorship: Improving Health Equity with Culturally Relevant Tobacco Cessation for Asian Populations

In 2020, almost 28% of PAF patients identified as African American.

HOW WE HELP

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. One event was held live in Memphis on February 29, 2020, where over 600 African American women convened. The other events were virtual and held over a series of months in Chicago as part of local PPE and food distribution initiatives that allowed for the sharing of information about breast cancer screening and PAF’s support services.
“Our case manager, Bridget, at PAF was warm, caring and very sympathetic with hearing my concerns... She also was proactive with seeing if we needed any other services going forward. We all need a “Bridget.” All of us are facing some sort of new adjustments in life and having people like her on the other end of that phone with a warm tone and compassionate heart can move you to your next blessing ... We were approved for the COVID-19 Emergency Food Grant, thank you guys so much!! God bless you and all that you do.”

— LaQuita, Ricky’s Wife

Ricky | Follicular Lymphoma

APPLICABLE RESOURCES & PROGRAMS:

PAF’s COVID Care program provides information and education in response to questions and concerns about accessing and paying for care and managing cost-of-living needs that have become difficult to manage due to the pandemic. Case managers ensure that individuals are quickly linked to resources while actively listening to patients’ questions and fears. Their goal is to provide empathetic, compassionate and knowledgeable support to each person they serve.

1-800-532-5274 or patientadvocate.org/covidcare/help/

PAF’s health equity team leveraged existing partnerships and built new ones to address gaps exposed by COVID-19 among populations at risk for health disparities. Partnerships with Sisters Working it Out, Carolyn and Karen Spiritual Healing House, AIAS-WINGS, Resurrection Project-ELLAS and Sister’s Network (Chicago Chapter) helped disseminate information about PAF’s COVID-19 support resources.

WHEN PAF PATIENTS IMPACTED BY THE PANDEMIC BUT NOT DIAGNOSED WITH COVID-19 WERE ASKED...

33% said they had trouble locating or accessing food and grocery delivery services since the beginning of the pandemic.

35% stated they had trouble paying for food since the beginning of the pandemic.

55% stated measures to stop the spread of COVID-19 affected their emotional and mental health.

2020 DATA POINTS:

28% of case management patients were African American, an increase of 43% over 2019.

Requests for nutrition/wellness assistance represented 10% of all the calls to PAF case managers.

23,866 patients received assistance from PAF COVID-19 financial support programs.

$10M in Grant Support provided to rheumatoid arthritis, cancer and multiple sclerosis patients in need of food assistance.

In partnership with Team Rubicon, PAF helped immunocompromised patients living with cancer, multiple sclerosis or rheumatoid arthritis whose ability to access or afford food and other nutritional needs was at risk due to COVID-19.

Team Rubicon mobilized volunteers to provide food pick-up and delivery assistance to 2,711 patients.
2020 Case Management Service by the Numbers

21,161
TOTAL CASE COUNT

302,359
CONTACTS MADE WITH OR ON BEHALF OF A PATIENT TO RESOLVE THEIR CASE

12
DAY AVERAGE TO WORK A CASE

HOW PATIENTS FIND PAF CASE MANAGEMENT SERVICES

Friend/Family: 13%
Government Agency or Representative: 1%
Healthcare Organization or Representative: 15%
Media and Outreach: 14%
Cases referred to PAF by other non-profit organizations: 53%
Patient previously served by PAF: 3%
Professional Organizations: 2%

ETNICITY

28% African American
.05% American Indian/Alaska Native
3% Asian
2% Blended Race
.08% Caribbean Islander
55% Caucasian
11% Hispanic/Latino
3% Middle Eastern
.2% Native Hawaiian/Other Pacific Islander

INCOME

47% <$23,999
28% $24,000 - $47,999
12% $48,000 - $71,999
6% $72,000 - $95,999
3% $96,000 - $119,999
5% $120,000 or More

EMPLOYMENT

22% Disabled
28% Employed
3% Full-time Student
1% Homemaker
1% Minor Child
23% Retired
2% Self-employed
20% Unemployed

AGE

3% Birth to 18
19% 19 to 35
30% 36 to 55
41% 56 to 75
7% Over 75

INSURANCE STATUS

83% Insured
17% Uninsured

CASE MANAGEMENT STAFF EXPERIENCE

95% of case management staff have some type of post-high school education
staff members speak Spanish

5
years of combined healthcare experience prior to coming to PAF

387
100%
have participated in some sort of job-related training

Diversity of backgrounds support the mission and core services

TOP 10 DIAGNOSIS CATEGORIES SERVED BY CASE MANAGEMENT

9% Autoimmune Diseases
63% Cancers
5% Cardiovascular Conditions
11% Chronic or Debilitating Conditions
3% Diabetes

2% Infectious Diseases
2% Kidney Diseases
7% Nervous System Conditions
2% Pulmonary Conditions
4% Vascular Diseases

9 NEW CPR DISEASE FUNDS LAUNCHED IN 2020

• Acromegaly
• COVID-19
• Gaucher Disease
• Hemophilia
• Hepatocellular Carcinoma
• Melanoma
• Metastatic Melanoma
• Pancreatic Cancer
• Spinal Muscular Atrophy

299 of those are navigation or case management experience

HOW WE HELP

TOP WAYS PAF CASE MANAGERS HELPED PATIENTS

8% Facilitated nutrition/food assistance
8% Negotiated financial discount on co-pay
7% Obtained utility financial relief
5% Secured ground transport
5% Located mortgage payment relief
4% Educated on disability eligibility and enrollment
4% Educated on health insurance eligibility and enrollment

71,115
Patients Approved

6
Average Contacts per Approved Applicant

$250,070,049
Grant Payment Total
16% Increase in the grant payment total

242,436
Incoming Calls Handled

764,010
Total # of Grant Payments

521,536
Patients Served by CPR Since 2004
“My Ophthalmologist prescribed a [therapy] that my insurance carrier denied ... I was promptly assigned to a PAF patient advocate. We worked together with immediacy to put together an appeal with an expedited review request ... thank goodness the efforts by PAF and everyone assisting me, helped me obtain the much-needed approval ... within days I received my treatment. Immediately my eyes started to improve. I felt like a flower that had wilted and when finally given water started to grow towards the sun again!”

Joyce | Graves & Thyroid Eye Diseases

APPLICABLE RESOURCES & PROGRAMS:

PAF’s Case Management Education Series, Helping Patients Chart their Course harnessed extensive expert case management knowledge to deliver a series of short webinars that teach individuals how to make informed health insurance decisions and address insurance denials. Each module includes skill tests and answer keys, sample documents, checklists, important terms and other helpful materials.

bit.ly/3C2zqn

Engaging with Insurers: Appealing a Denial, available in print and online, focuses on patients’ rights, effective communication, self-advocacy and navigation through health insurance denials.

patientadvocate.org/download-view/engaging-with-insurers-appealing-a-denial

Of PAF’s 31 case management programs, 15 assist people living with cancer while 16 assist people living with a condition other than cancer, including infectious diseases, cardiac conditions, sickle cell anemia, ALS and Inflammatory Bowel Disease.

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

2020 DATA POINTS:

Distinct Patient Diagnoses:

629

Of those diagnosed:

246 were Distinct Rare Diseases

Case Management

Total Case Management Closed Cases 20,623
Total Issues Addressed 28,523
Total PAF Case Management Contacts 302,339
Average Contacts per Case 15

WHEN PAF PATIENTS WERE ASKED...

34% OF PATIENTS reported that challenges with insurance coverage was a barrier to achieving their healthcare goals

78% OF PATIENTS stated that PAF assisted them in achieving their healthcare goals

40% OF PATIENTS reported being “very concerned” about having access to the best medical care during their treatment journey

(PAF 2019 Retrospective Survey)
The Evolving Landscape of Research, Dissemination, Partnerships & Patient Experience

Early in the COVID-19 pandemic, PAF health services research team developed an analytical framework to capture the unique experience of our patients – using this information to strengthen and diversify our services, partnerships and dissemination activities.

We launched a series of surveys to collect information about how the pandemic impacted various aspects of our patients’ lives. Approximately 4,000 patients nationwide (27% response rate) responded to the baseline survey disseminated in June and July 2020.

COVID-19 Effect

87% of the patients surveyed felt their condition put them at higher risk for severe illness if they were to be diagnosed with COVID-19

42% stated “staying healthy” was their greatest need related to the COVID-19 pandemic

18% believed “financial security” was the top need related to COVID-19

55% stated measures to stop the spread of COVID-19 affected their emotional and mental health

1 of 3 patients experienced financial hardship after the implementation of public health measures to stop the spread of COVID-19

Work Disruption

78% of patients reported some form of work disruption due to COVID-19

35% transitioned to a work-from-home/telework environment

47% reduced hours worked

12% experienced a furlough

10% were laid off or lost their employment

Healthcare Access Challenges

55% said they had healthcare access challenges related to the treatment of non-COVID-19 related illnesses

53% reported challenges in keeping or receiving appointments for specialty care doctors

46% reported challenges in keeping or receiving appointments for dental services

45% reported challenges in keeping or receiving appointments for primary care physician

32% reported challenges in keeping or receiving appointments for laboratory or diagnostic testing

Accessing Care

64% of patients stated they changed the way they accessed care

71% of patients reported 2 or more telehealth visits since the beginning of the COVID-19 pandemic

40% reported being “extremely satisfied” with care received during a telehealth visit

50% patients experienced care delays or treatment interruptions due to COVID-19

82% were “extremely” or “very” concerned about the long-term health issues related to these disruptions

PATIENT ENGAGEMENT AWARDS

PAF received a 2-year PCORI Engagement Award, entitled Paving a Pathway to Engage Underserved Populations in Research. This project aims to increase the capacity of our current patient network with a focus on giving underserved patients and caregivers a voice in the research ecosystem.

In partnership with AcademyHealth, PAF was also selected by the Patient-Centered Outcomes Research Institute (PCORI®) to serve as the Engagement Coordinating Center (ECC) for PCORNet®, the National Patient-Centered Clinical Research Network. The project’s goal is to increase the engagement of patients, caregivers and community members to participate in and inform the nation’s clinical research.

DISSEMINATION ACTIVITIES

Dissemination into the areas of healthcare delivery systems, health policy, public health and cardiovascular disease is an important component of the research process, and the utilization of PAF’s research findings is an organizational priority.

RESEARCH ACTIVITIES AND PARTNERSHIPS

Examples of Data Analysis and Dissemination Partnerships

• University of North Carolina at Chapel Hill – Examining the impact of cancer diagnosis on employment and the role of the employers in supporting newly diagnosed cancer patients.

• University of Alabama at Birmingham/MD Anderson Medical Center – Comprehensive review of PAF’s COVID-19 survey data.

Academic & Non-Profit Grant Funded Research

<table>
<thead>
<tr>
<th>ORGANIZATION</th>
<th>PROJECT</th>
<th>LOCATION</th>
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<tbody>
<tr>
<td>Fred Hutchinson Cancer Research Center</td>
<td>Randomized pragmatic trial of a proactive financial navigation intervention in patients with newly diagnosed gastric and gastroesophageal junction (G3EJ) adenocarcinoma</td>
<td>Seattle, WA</td>
</tr>
<tr>
<td>Fred Hutchinson Cancer Research Center</td>
<td>A randomized trial addressing cancer-related financial hardship through delivery of a proactive, financial navigation intervention (G3EJ)</td>
<td>Multiple US locations</td>
</tr>
<tr>
<td>LUNGevity Foundation</td>
<td>Project DIRECT: Eliminating disparities in lung cancer comprehensive biomarker testing</td>
<td>National Sample: Online Survey</td>
</tr>
<tr>
<td>Emory University/ECOG ACERIN Cancer Research Group</td>
<td>Oral chemotherapy non-adherence among breast cancer patients during a pandemic: a feasibility trial (ECORDER)</td>
<td>Atlanta, GA</td>
</tr>
<tr>
<td>University of North Carolina at Chapel Hill</td>
<td>Ensuring the impact of financial toxicity: Improving the reach and quality of cancer care in rural populations (EFT)</td>
<td>Multiple NC locations</td>
</tr>
<tr>
<td>NORC at the University of Chicago</td>
<td>Patient-Driven Research Communities (PDRC) Learning Network</td>
<td>Chicago, IL</td>
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</table>

Data highlights from 2020 research and evaluation projects are presented throughout the report.
Patient Congress
Historically, PAF’s annual Patient Congress event has convened in Washington, DC. Event plans were adapted this year to provide a series of coordinated outreach, education and skills development activities in virtual sessions.

Patient Congress 2020: Finding Community Through Advocacy, held virtually September 23-25, brought together more than 150 volunteers, patients, caregivers and advocacy partners and showcased strategic solutions to minimize cost burdens and meet patients’ and families’ most pressing financial and social needs. The keynote address featured guest speaker Mia Keeys of the American Medical Association’s Center for Health Equity. PAF CEO Alan Balch and EVP Shonta Chambers discussed the impact of policies on improving health equity, as well as PAF services to address gaps in financial and social needs.

To learn more about Patient Congress, visit npaf.org/what-we-do/our-work/patient-congress-2020

Scholarship for Survivors
Since the program’s inception in 2000, the Scholarship for Survivors program has awarded more than $730,000 in scholarships to 126 deserving college students whose educational pursuits were disrupted due to a serious illness. PAF, along with many other gracious sponsors and donors, has enabled 54 of these highly motivated, courageous young adults to realize fully degreeed graduation. The program currently supports 30 students still pursuing their course of study. Scholarship recipients are eligible to receive $3,000 per school year for four consecutive years.

To learn more about our scholarship program patientsadvocate.org/scholarships

Congratulations to the New 2020 – 2021 Scholarship Winners

Ashley | St. John’s University, Psychology
Bianca | NOVA Southeastern University, Pediatric Oncology
Brandon | University of Florida, Psychology/Pre-Med
Gianna | St. John’s University, Political Science/Pre-Law
Graice | Hope College, Biomedical Engineering
Isobelle | Duke University, Neuroscience, Psychology
Jessica | High Point University, Media Production
Kaela | Virginia Commonwealth University, Medicine
Kayla | University of Miami, Public Advocacy
Lauren | Capital University, Pediatric Oncology Nursing
Lydia | Stanford University, Biology/Neurobiology
Rowan | Colorado College, Business Administration
Yhan | Icahn School of Medicine at Mt. Sinai, Medicine

In addition to the new awardees above, PAF’s scholarship program will also support 17 returning students this academic year.

Promise of Hope
PAF’s premiere fundraising gala, A Promise of Hope Affair, was “Big Hats & Bow Ties” themed and celebrated its 20th year in February of 2020.

25 event sponsors
370+ guests from across the nation
$214,000 raised
30 scholarships funded (increased from 25)

To learn more, please visit promiseofhope.net

Crawlin’ Crab
Due to the impact of COVID-19, the event was transitioned to a virtual run and fundraising campaign held between October 3-25.

5 Teams
23 fundraisers
167 supporters
$22,000 raised

To learn more and watch a PAF testimonial video, please visit crawlincrabhalf.com/charities

“Cancer has had a profound impact on me. Both my brother and I have a rare genetic disorder called Li-Fraumeni Syndrome, a predisposition to all forms of cancer. Between the two of us, we have battled cancer 9 times. With the help from PAF, I am pursuing a career as a pediatric oncology nurse and plan to use my experiences to help others. My hope is that in seeing a former pediatric cancer patient who has both survived and thrived, my patients might be encouraged and feel less alienation than I did. Thank you for your support!”  

– Lauren | Scholarship Recipient

To learn more and watch a PAF testimonial video, please visit tiny.cc/parkerprofile
Financial Statements

PAF financial statements are based on its fiscal year, from July of 2019 to June of 2020. The program impact reporting in the preceding pages is conducted on an annual basis, from January 2020 to December 2020.

**SUMMARY OF TOTAL PATIENT IMPACT IN FISCAL YEAR 2019/20**

<table>
<thead>
<tr>
<th>Total Patient Cases</th>
<th>188,696</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Case Management Cases</td>
<td>21,231</td>
</tr>
<tr>
<td>Total Co-Pay Relief Cases</td>
<td>72,906</td>
</tr>
<tr>
<td>Total Financial Support Programs Cases</td>
<td>67,637</td>
</tr>
<tr>
<td>PAF COVID Financial Support</td>
<td>14,431</td>
</tr>
<tr>
<td>Total Patient Services Email Helpline Sessions</td>
<td>12,491</td>
</tr>
<tr>
<td>Total Patient Services Case Contacts</td>
<td>1,301,755</td>
</tr>
</tbody>
</table>

**SUMMARY OF CASE MANAGEMENT IMPACT IN FISCAL YEAR 2019/20**

| Total PAF Case Management Case Count | 21,386* |
| Unique Case Management Patient Issues | 36,240 |
| Total PAF Case Management Contacts | 334,734 |
| Average Contacts per Case | 15.7 |

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

**FINANCIAL STATEMENTS**

**Patient Advocate Foundation Statements of Financial Position June 30, 2020 and 2019**

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General operating cash and cash equivalents</td>
<td>$34,643,003</td>
<td>$28,077,632</td>
</tr>
<tr>
<td>Restricted cash and cash equivalents</td>
<td>$172,931,062</td>
<td>$250,800,565</td>
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<tr>
<td>Unconditional promises to give</td>
<td>$14,086,492</td>
<td>$17,254,062</td>
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<tr>
<td>Accounts receivable</td>
<td>$1,611,627</td>
<td>$518,498</td>
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<tr>
<td>Interest receivable</td>
<td>$266,096</td>
<td>$18,437</td>
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<tr>
<td>Due from National Patient Advocate Foundation</td>
<td>$41,713</td>
<td>$2,078,900</td>
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<tr>
<td>Investments and cash equivalents</td>
<td>$127,186,163</td>
<td>$42,269</td>
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<tr>
<td>Inventories</td>
<td>$55,002</td>
<td>$412,217</td>
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<tr>
<td>Prepaid expenses</td>
<td>$471,457</td>
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</tr>
<tr>
<td>Total current assets</td>
<td>$351,292,615</td>
<td>$299,222,580</td>
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<tr>
<td>Property and equipment, net</td>
<td>$3,919,924</td>
<td>$4,321,760</td>
</tr>
<tr>
<td>Other assets</td>
<td>$50,331</td>
<td>$50,331</td>
</tr>
<tr>
<td>$355,262,870</td>
<td>$303,594,671</td>
<td></td>
</tr>
</tbody>
</table>

| LIABILITIES AND NET ASSETS |       |      |
| Current liabilities |       |      |
| Accounts payable and accrued expenses | $13,105,119 | $3,763,880 |
| Due to National Patient Advocate Foundation | $52,641 | $10,290 |
| Postretirement benefits liability, current portion | $48,930 | $34,233 |
| Deferred revenue | $19,151,391 | $16,670,044 |
| Accrued vacation leave | $569,698 | $462,147 |
| Total current liabilities | $32,927,779 | $20,940,594 |
| Long-term liabilities |       |      |
| Postretirement benefits liability, less current portion | $4,348,581 | $3,137,549 |
| Incurred but not recorded liabilities | $135,687 | $126,804 |
| Total long-term liabilities | $4,284,268 | $3,264,353 |
| Total liabilities | $37,212,047 | $24,204,947 |
| Net assets without donor restrictions |       |      |
| Undesignated | $16,262,233 | $13,272,753 |
| Board designated | $2,186,163 | $2,078,900 |
| Total net assets without donor restrictions | $18,448,396 | $15,351,653 |
| Net assets with donor restrictions |       |      |
| Restricted by purpose | $299,602,427 | $264,038,071 |
| Total net assets | $318,050,823 | $279,389,724 |
| Total liabilities and net assets | $355,262,870 | $303,594,671 |
2020

Donor

$3,759,260

Private and public donations

36,924

Patient Congress

125,000

Promise of Hope

75,000

Patient Action Council

-3,096,743

Investment return

3,882,221

Restrictions

-18,618,857

Restrictions

141,650

Support of Congress

75,000

Financial aid programs

5,234,955

Supporting services:

-2,860,826

Postretirement benefit charges other than periodic cost

-689,077

Change in net assets from operations

35,564,356

Total revenues, gains and other support

246,082,505

Change in net assets

35,564,356

Financial aid programs

5,575,996

Donor

3,096,743

Investment return

3,882,221

Restrictions

-18,618,857

Restrictions

141,650

Support of Congress

75,000

Financial aid programs

5,234,955

Supporting services:

-2,860,826

Postretirement benefit charges other than periodic cost

-689,077

Change in net assets from operations

35,564,356

Total revenues, gains and other support

246,082,505

Change in net assets

35,564,356

Financial aid programs
Scientific Advisory Committee

Al Benson III, MD, FACP
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Professor of Medicine
Associate Director for Clinical Investigations
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Director of Imaging Program at DCRI
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University of Washington

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Dartmouth-Hitchcock & Geisel School of Medicine

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Knoxville

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Case Manager
13 years with PAF

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Case Management
Senior Director
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Case Manager
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Case Manager and Quality Assurance Coordinator
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Rita Matthews
Case Manager
16 years with PAF

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Bill Nason, MBA, Chief Financial Officer
Carey Waldrip, Director of Special Projects
Eric Anderson, Chief of Mission Delivery
Fran Castellow, MS Ed, President of Operations
Jennifer Brewer, MBA, Senior Director of Financial Support Programs

Kathleen Gallagher, MPH, Senior Director of Health Services Research
Rebekah Angone, PhD, Vice President for Patient Experience & Program Evaluation
Shawn Nason, Director of Events & Donor Campaigns
Shanta Chambers, MSW, Executive Vice President, Health Equity & Community Engagement

Howell Creative Group

PAF’s Legacy of Service Continues

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Design
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Rita Matthews
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16 years with PAF
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.