Letter from the CEO

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
**Overall Foundation Impact**

Summary of PAF Total Patient Cases and Contacts in 2020

- Total Patient Case Count: 192,881
- Case Management Cases: 21,161
- Co-Pay Relief Recipients: 71,115
- Financial Aid Fund Recipients: 61,197
- PAF COVID Financial Support Recipients: 23,866
- Patient Services Email Helpline Sessions: 15,542

**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 was 32%, 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

4.9 of 5

- Knowledge & professionalism of staff

- 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

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

**Case Management**

- 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**

- 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

**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**

- Service to All 50 States
- Increased by 32% over 2019
- Total Patients Served by PAF Between 1996 and 2020: 1,556,713

**Diagnoses Served by PAF**

- 629 distinct patient diagnoses
- 246 distinct rare diseases

**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.
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
- Expanded FMLA protections for our staff

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.

Case Management

Financial Services

CO-PAY RELIEF

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.

FINANCIAL ASSISTANCE FUNDS

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.

NON-PROFIT SERVICE PARTNERSHIPS

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.

22% of case management patients report being disabled
47% of case management patients earn $23,999 or less annually
$25M+ in debt relief obtained on behalf of patients

$250M+
CPR grant payments to patients in need

4 new financial assistance funds launched in 2020
1 of 3 patients participating in a PAF pandemic survey reported financial hardship after implementation of state/federal responses to COVID-19
270k incoming calls handled by financial call counselors, a 66% increase over 2019

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.

tiny.cc/welcometocpr
tiny.cc/weareeveryone
FINANCIAL IMPACT

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.

A Legacy of Service

PATIENT IMPACT: THE BENNARDO FAMILY’S STORY

December 27, 2019

Dear Friends at Patient Advocate Foundation:

In 2016, my wife Tammy had already been battling primary brain cancer for 5 years. As you might imagine, the costs of coping with medical care for a debilitating and life-limiting disease wereastronomical.

Tammy had just completed her second brain surgery, and was mentioning a count-down to the day when the complexity of chemo and radiation treatments would begin.

Someone introduced us to Patient Advocate Foundation (PAF) who quickly came in and offered us financial support to cover some of the impact of our medical bills.

I cannot begin to express the impact your support, encouragement, and financial help made on us during a very, very difficult time.

Sadly, Tammy lost her battle with brain cancer in 2017. When she was diagnosed in 2006, she was expected to live for 6 months. Tammy lived for 10 years after her diagnosis. Our daughters were able to be raised into their mid-teens with years by their mother who loved them, an end.

I have always been grateful for the help of PAF, and have always wanted to give back, even if in some small way.

Attached please find a check. It is a small gift, but we hope it will be of some help to those who are facing the challenges you have.

Thank you so much for all you did for our family, and for all you do for everyone else you serve.

Very truly yours,

[Signatures]

APPLICABLE RESOURCES & PROGRAMS:

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

85,063 PATIENTS ASSISTED

256k+ INDIVIDUAL GRANT PAYMENTS PROCESSED

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)

58% of patients reported that out-of-pocket medical costs were a significant barrier to achieving healthcare goals (PAF 2019 Retrospective Survey)

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)

2020 DATA POINTS:

Case management gender:

63% Female

37% Male

Featured on this page, the Bennarido family

25TH ANNIVERSARY

PATIENT IMPACT: THE BENNARDO FAMILY’S STORY

63% OF PATIENTS

58% OF PATIENTS

32% OF PATIENTS
**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 communication 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 extensive catalog of content in an easily accessible, searchable format, crossing category filters for 13 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

**National Financial Resource Directory 2020 Highlights**

- Received the Bronze medal award in the 22nd Annual Digital Health Awards®
- 10% increase in average daily use compared to 2019
- 34,869 total searches completed by users
- 773k matching resources provided to users

**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

**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 65% increase over 2019, with more than 5,000 unique visitors, a 74% increase.

**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

"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

**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

**PAF’s new publication:** Getting the Right Test at the Right Time: A Cancer Patient’s Guide to Biomarkers, addresses misconceptions 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/
In 2020, almost 28% of PAF patients identified as African American.

### 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 3% as American Indian/Alaska Native.

![In 2020, SMHN’s three webinar trainings (selfmadeshell.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

PAF’s Progress in Reaching Underserved Patients

<table>
<thead>
<tr>
<th>Year</th>
<th>African American</th>
<th>Hispanic/Latino</th>
<th>Asian</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>1%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>2007</td>
<td>12%</td>
<td>6%</td>
<td>1%</td>
</tr>
<tr>
<td>2012</td>
<td>18%</td>
<td>13%</td>
<td>2%</td>
</tr>
<tr>
<td>2017</td>
<td>20%</td>
<td>11%</td>
<td>3%</td>
</tr>
<tr>
<td>2020</td>
<td>28%</td>
<td>8%</td>
<td>1%</td>
</tr>
</tbody>
</table>

### PAF’s Health Equity Accomplishments

- **>1,750** Estimated viewers reached with lymphedema educational video produced in partnership with Live Today Foundation.
- **10k** Estimated viewers 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.

### How We Help

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-ELAS (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 health disparities. SMHN focuses on the implementation of evidenced-based strategies that address cancer and tobacco-related disparities among populations with low socio-economic characteristics.

# on the ground collaborative partners in 2020 included:

- The Black Breast Cancer Alliance
- The Young Survival Coalition
- Resurrection Project-ELAS (En La Lucha a Sobrevivir)
- Sister’s Network (Chicago & Memphis chapter)
- ALAS-WINGS

[PAF health equity accomplishments](#)

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.

[PAF’s Shonta Chambers, MSW, at the Memphis Breast Cancer Event, February 2020.](#)
Ricky | Follicular Lymphoma

“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

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, ALAS-WINGS, Resurrection Project-ELAS 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

$10M IN GRANT SUPPORT

provided to rheumatoid arthritis, cancer and multiple sclerosis patients in need of food assistance

Team Rubicon mobilized volunteers to provide food pick-up and delivery assistance to 2,711 patients

IN GRANT SUPPORT

provided to rheumatoid arthritis, cancer and multiple sclerosis patients in need of food assistance

Team Rubicon mobilized volunteers to provide food pick-up and delivery assistance to 2,711 patients

23,866 patients received assistance from PAF COVID-19 financial support programs
# 2020 Case Management Service by the Numbers

**Total Case Count**: 21,161

**Total Contacts Made**: 302,359

**Day Average to Work a Case**: 12

**Increase of 31% from 2019**

## How Patients Find PAF Case Management Services

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friend/Family</td>
<td>13%</td>
</tr>
<tr>
<td>Government Agency or Representative</td>
<td>1%</td>
</tr>
<tr>
<td>Healthcare Organization or Representative</td>
<td>15%</td>
</tr>
<tr>
<td>Media and Outreach</td>
<td>14%</td>
</tr>
<tr>
<td>Cases referred to PAF by other non-profit organizations</td>
<td>53%</td>
</tr>
<tr>
<td>Patient previously served by PAF</td>
<td>3%</td>
</tr>
<tr>
<td>Professional Organizations</td>
<td>2%</td>
</tr>
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## Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>28%</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>0.5%</td>
</tr>
<tr>
<td>Asian</td>
<td>3%</td>
</tr>
<tr>
<td>Blended Race</td>
<td>2%</td>
</tr>
<tr>
<td>Caribbean Islander</td>
<td>0.08%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>55%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>11%</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>3%</td>
</tr>
<tr>
<td>Native Hawaiian/Other Pacific Islander</td>
<td>3%</td>
</tr>
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</table>

## Income

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>$0 - $23,999</td>
<td>47%</td>
</tr>
<tr>
<td>$24,000 - $47,999</td>
<td>28%</td>
</tr>
<tr>
<td>$48,000 - $71,999</td>
<td>12%</td>
</tr>
<tr>
<td>$72,000 - $95,999</td>
<td>6%</td>
</tr>
<tr>
<td>$96,000 - $119,999</td>
<td>3%</td>
</tr>
<tr>
<td>$120,000 or More</td>
<td>5%</td>
</tr>
</tbody>
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## Employment

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled</td>
<td>22%</td>
</tr>
<tr>
<td>Employed</td>
<td>28%</td>
</tr>
<tr>
<td>Full-time Student</td>
<td>3%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1%</td>
</tr>
<tr>
<td>Minor Child</td>
<td>1%</td>
</tr>
<tr>
<td>Retired</td>
<td>23%</td>
</tr>
<tr>
<td>Self-employed</td>
<td>2%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>20%</td>
</tr>
</tbody>
</table>

## Age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 18</td>
<td>3%</td>
</tr>
<tr>
<td>19 - 25</td>
<td>19%</td>
</tr>
<tr>
<td>26 - 35</td>
<td>19%</td>
</tr>
<tr>
<td>36 - 55</td>
<td>30%</td>
</tr>
<tr>
<td>56 - 75</td>
<td>30%</td>
</tr>
<tr>
<td>76 or Older</td>
<td>7%</td>
</tr>
</tbody>
</table>

## Insurance Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insured</td>
<td>83%</td>
</tr>
<tr>
<td>Uninsured</td>
<td>17%</td>
</tr>
</tbody>
</table>

## Top Ways PAF Case Managers Helped Patients

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitated nutrition/food assistance</td>
<td>8%</td>
</tr>
<tr>
<td>Negotiated financial discount on co-pay</td>
<td>8%</td>
</tr>
<tr>
<td>Obtained utility financial relief</td>
<td>7%</td>
</tr>
<tr>
<td>Secured ground transport</td>
<td>5%</td>
</tr>
<tr>
<td>Located mortgage payment relief</td>
<td>5%</td>
</tr>
<tr>
<td>Educated on disability eligibility and enrollment</td>
<td>4%</td>
</tr>
<tr>
<td>Educated on health insurance eligibility and enrollment</td>
<td>4%</td>
</tr>
</tbody>
</table>

## Top 10 Diagnosis Categories Served by Case Management

- **Autoimmune Diseases**: 9%
- **Cancers**: 63%
- **Cardiovascular Conditions**: 5%
- **Chronic or Debilitating Conditions**: 11%
- **Diabetes**: 3%
- **Infectious Diseases**: 2%
- **Kidney Diseases**: 2%
- **Nervous System Conditions**: 7%
- **Pulmonary Conditions**: 2%
- **Vascular Diseases**: 4%

### Diversity of Backgrounds Support the Mission and Core Services

- 100% have participated in some sort of job-related training
- 5 staff members speak Spanish
- 387 years of combined healthcare experience prior to coming to PAF
- 95% of case management staff have some type of post-high school education
- 16% increase in the grant payment total
- 11% increase in the Unemployed category
- 11% increase in referrals from friends and family
- 45% increase in the number of uninsured patients
“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 skills tests and answer keys, sample documents, checklists, important terms and other helpful materials. bit.ly/3C2zn

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

Our expert case management assistance is often sought out by patients experiencing complex healthcare barriers that require expedient intervention, sustained involvement and effective collaboration between multiple stakeholders to reach resolution.

CASE MANAGEMENT

Our expert case management assistance is often sought out by patients experiencing complex healthcare barriers that require expedient intervention, sustained involvement and effective collaboration between multiple stakeholders to reach resolution.

2020 DATA POINTS:

Distinct Patient Diagnoses: 629
Of those diagnosed: 246 were Distinct Rare Diseases

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)

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 skills tests and answer keys, sample documents, checklists, important terms and other helpful materials. bit.ly/3C2zn

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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
The Evolving Landscape of Research, Dissemination, Partnerships & Patient Experience

Early on 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 physicians
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

P A T I E N T  E N G A G E M E N T  A W A R D S
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.

D I S S E M I N A T I O N  A C T I V I T I E S
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.

A B S T R A C T S
Examples:
“Matters of the Heart – Navigating Resources to Assist Patients in Managing Cardiovascular Conditions,” poster and presentation at 26th Annual Cardiovascular Nursing Symposium. Innovation category winner.

“Ensuring nutritional access in the time of COVID-19. A multi-organizational approach providing support to immunocompromised individuals struggling with food insecurity,” presented at the American Public Health Association conference by Fran Castellow, MSED, PAF President of Operations; APHA’s 2020 VIRTUAL Annual Meeting and Expo (Oct. 24-28)

P U B L I S H E D  J O U R N A L  A R T I C L E S
Examples:


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>
</tr>
</thead>
<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 (GEJ) 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 (CREDIT)</td>
<td>Multiple US locations</td>
</tr>
<tr>
<td>LUNGevity Foundation</td>
<td>Project DIRECT: Eliminating disparities in lung cancer screening.</td>
<td>National Science Foundation Online Survey</td>
</tr>
<tr>
<td>Emory University/ECOG ACRI Cancer Research Group</td>
<td>Oral chemotherapy non-adherence among breast cancer patients during a pandemic: a feasibility trial (ECONLIP)</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 (ELIP)</td>
<td>Multiple NC locations</td>
</tr>
<tr>
<td>NDRC at the University of Chicago</td>
<td>Patient-Directed Research Communities (PDRC) Learning Network</td>
<td>Chicago, IL</td>
</tr>
</tbody>
</table>

Data highlights from 2020 research and evaluation projects are presented throughout the report.
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

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 degreed 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.

Learn more about our scholarship program patientadvocate.org/scholarships

Scholarship for Survivors

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

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 |
| Gracie | Hope College, Biomedical Engineering |
| Isabelle | Duke University, Neuroscience, Psychology |
| Jessica | High Point University, Media Production |
| Keela | 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.

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

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

tiny.cc/parkerprofile

More than 150 attendees participated virtually.
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

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

<table>
<thead>
<tr>
<th><strong>ASSETS</strong></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>
</tr>
<tr>
<td>Unconditional promises to give</td>
<td>$14,086,492</td>
<td>$17,254,062</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>1,611,627</td>
<td>518,498</td>
</tr>
<tr>
<td>Interest receivable</td>
<td>266,096</td>
<td>-</td>
</tr>
<tr>
<td>Due from National Patient Advocate Foundation</td>
<td>41,713</td>
<td>18,437</td>
</tr>
<tr>
<td>Investments and cash equivalents</td>
<td>127,166,163</td>
<td>2,078,900</td>
</tr>
<tr>
<td>Inventories</td>
<td>35,002</td>
<td>42,269</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>471,457</td>
<td>412,217</td>
</tr>
<tr>
<td>Total current assets</td>
<td>$351,292,615</td>
<td>$299,222,580</td>
</tr>
<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><strong>Total assets</strong></td>
<td>$355,262,870</td>
<td>$303,594,671</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 | $48,920 | $34,233 |
| Deferred revenue | $19,151,391 | 16,670,444 |
| 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 | $4,148,581 | $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 |
### Financial Statements

**Years Ended June 30, 2019 and 2020**

#### OPERATING REVENUES

<table>
<thead>
<tr>
<th>Category</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grants</td>
<td>$258,937</td>
<td>$165,787</td>
</tr>
<tr>
<td>Private and public donations</td>
<td>$35,314</td>
<td>$35,314</td>
</tr>
<tr>
<td>Donated services and materials</td>
<td>$80,000</td>
<td>$80,000</td>
</tr>
<tr>
<td>Promise of Hope</td>
<td>$125,000</td>
<td>$75,000</td>
</tr>
<tr>
<td>Investment return</td>
<td>$(238,734,798)</td>
<td>$(235,446,577)</td>
</tr>
<tr>
<td><strong>Total revenues, gains and other support</strong></td>
<td><strong>$301,253,379</strong></td>
<td><strong>$262,259,451</strong></td>
</tr>
</tbody>
</table>

#### OPERATING EXPENSES

<table>
<thead>
<tr>
<th>Category</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service contracts</td>
<td>$5,867,102</td>
<td>$246,082,505</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$2,860,826</td>
<td>$1,085,844</td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td><strong>$257,775,186</strong></td>
<td><strong>$257,775,186</strong></td>
</tr>
</tbody>
</table>

#### Net assets, beginning of year

<table>
<thead>
<tr>
<th>Category</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>$264,038,071</strong></td>
<td><strong>$281,708,429</strong></td>
</tr>
</tbody>
</table>

#### Net change in net assets

<table>
<thead>
<tr>
<th>Category</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>$35,564,356</strong></td>
<td><strong>$39,604,033</strong></td>
</tr>
</tbody>
</table>

#### Net assets, end of year

<table>
<thead>
<tr>
<th>Category</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>$299,602,427</strong></td>
<td><strong>$321,312,462</strong></td>
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</table>

### Supporters

**3 Blues of Color**  
**AbbieS**  
**AcademyHealth**  
**Ace Peninsula Hardware**  
**Ampersand**  
**Anta Bi**  
**Baltimore Orioles**  
**Barbara Baldridge**  
**Bec Concerned**  
**Bermuda Bob**  
**Beth Moore & Associates**  
**Big Woody’s Bar and Grill**  
**Bite & Build**  
**Bobby’s Bar & Grill**  
**Brenda’s Bakery**  
**Brenna’s Bakery**  
**Brooke Donahue**  
**Brownsville Brewing Company**  
**Bryan Center**  
**Bryan and Fran Castellow**  
**Bryan Agnew**  
**Bryan Agnew**  
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**Bryan and Fran Castello...
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Chair, Scientific Advisory Committee
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Associate Director for Clinical Investigations
Robert H. Lurie Comprehensive Cancer Center of Northwestern University

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Leo Sands
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US Oncology (Retired)

Doris Simonson
Mother of Cheryl Grimmel

Carlette Hotett, MBA
Case Manager
13 years with PAF

Jasmine Pugh, LLM
Case Manager
5 years with PAF

Katyae Shively, CCMA
Case Manager and Quality Assurance Coordinator
12 years with PAF

Beth Hoer, Grants Manager

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

Design
Howell Creative Group

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Design
Howell Creative Group
O U R  M I S S I O N

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.

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