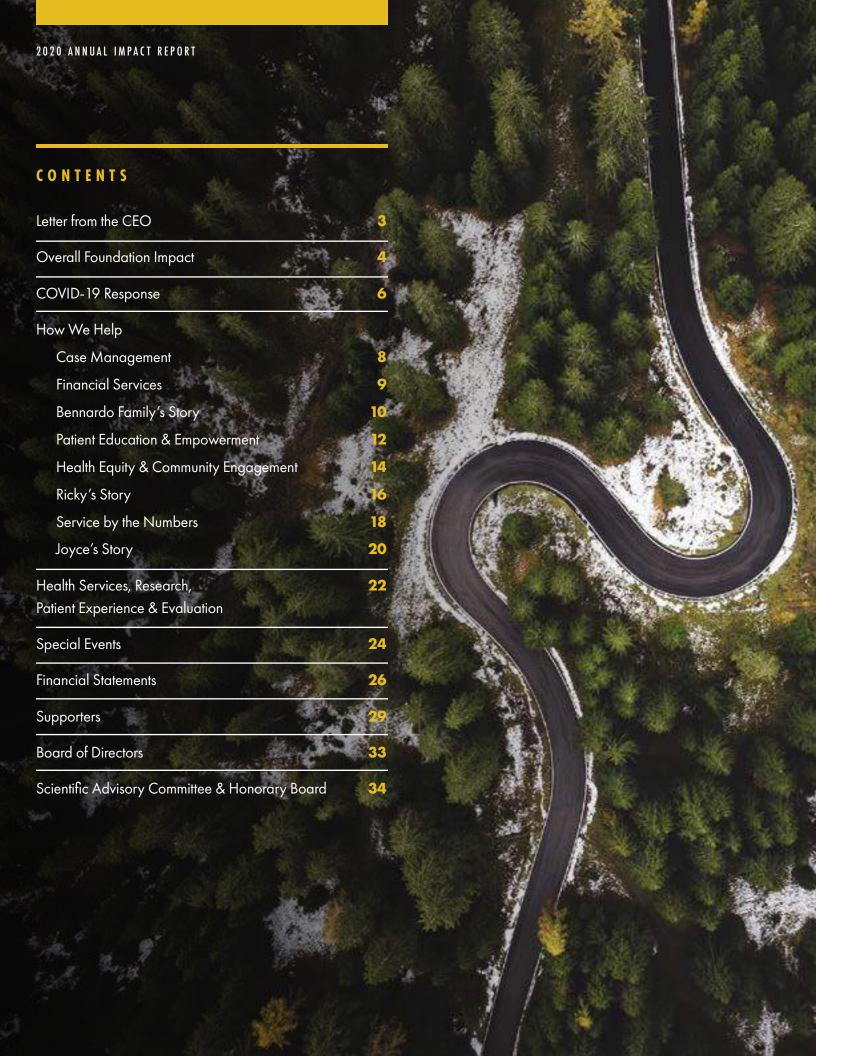


PATIENT ADVOCACY

by supporting patient journeys



2020 ANNUAL IMPACT REPORT



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.







tiny.cc/ceointroduction

OUR HISTORY

PAF was founded in 1996 by Nancy Davenport-Ennis and co-founded by John H. (Jack) Ennis to help address the issues faced by patients like their friend Cheryl Grimmel, who had to battle not only her breast cancer but for access to affordable treatments. In PAF's first year, Nancy and a part-time volunteer staff of 2 provided case management assistance to 157 patients who faced barriers to prescribed care. Fast forward to 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

increased by 32% over 2019

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	<i>7</i> 1,115
Financial Aid Fund Recipients	61,197
PAF COVID Financial Support Recipients	23,866
Patient Services Email Helpline Sessions	15,542

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

patient assistance programs provide financial support to patients across

- 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

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



Management

99%

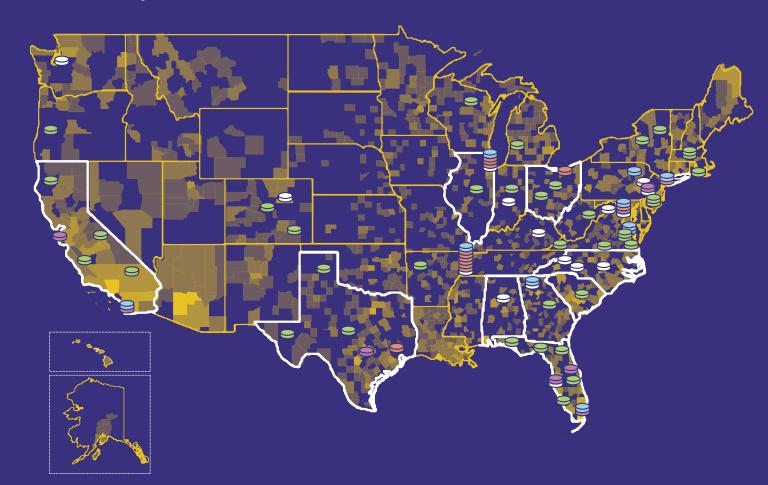


Financial Aid Funds

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.



PAF Population Hotspot Indicators

- Less than 10
- 11-100 Patients
- 101-500 Patients
- 101-300 raileriis
- 501-1,000 Patients
- > 1,001 Patients

PAF National Impact

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

☐ PAF Top 10 Patient Service States

Florida: 12% North Carolina: 5%
Georgia: 10% Alabama: 5%
Texas: 8% South Carolina: 5%

California: 6% Ohio: 4%

New York: 5% 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
- Expanded FMLA 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 patientadvocate.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 5, 2020)
- COVID-19 Emergency Food Assistance Program
 In partnership with Team Rubicon and Bristol Myers
 Squibb Foundation (serving patients through July 16, 2020)

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.



COVID-19 Response Key

National Response

February 29: CDC and Washington

State report the first US COVID-19 death?

Sources: 1ajmc.com/view/a-timeline-of-covid 19-developments-in-2020 (unless otherwise cited) | 2 cdc.gov/media/releases/2020/s0229-COVID-19-first-death.html | 3 cdc.gov/mmwr/volumes/69/wr/mm6935a2.htm#:~:text=The%20first%20territorial%20order%20was,stay%2Dat%2Dhome%20orders | 4 irs.gov/newsroom/economic-impact-payments-what-you-need-to-know | 5 ajmc.com/view/cost-concerns-would-prevent-millions-of-americans-from-seeking-covid 19-care-survey-finds | 6 cnn.com/world/live-news/coronavirus-pandemic-06-30-20-intl/index.html | 7 ajmc.com/view/states-facing-covid 19-spikes-report-greatest-health-insurance-coverage-losses | 8 voanews.com/covid-19-pandemic/us-coronavirus-cases-rise-month-over-month-27-states-september | 9 cnbc. com/2020/12/04/jobs-report-november-2020.html#:~:text=There%20are%20still%2010.7%20million,up%202.5%20million%20from%20February | 10 nbcnews.com/news/us-news/december-was-deadliest-most-infectious-month-start-pandemic-n1252645

HOW WE HELP HOW WE HELP

Case Management



tiny.cc/weareeveryone

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.

NON-PROFIT SERVICE PARTNERSHIPS

Eleven of our case management programs are fully funded by donations and grants from nonprofit 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.

OF CASE MANAGEMENT **PATIENTS** report being disabled

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

IN DEBT RELIEF obtained on behalf of patients

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.



new financial assistance funds launched in 2020



patients participating in a PAF pandemic survey reported financial hardship after implementation of state/federal responses to COVID-19



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.

CPR grant payments to patients in need



A Legacy of Service

December 22, 2020

Dear Friends at Patient Advocate Foundation:

In 2006, my wife Tammy had already been battling primary brain cancer for 6 years. As you might imagine, the costs of ongoing medical care for a debilitating and life-threatening disease become unmanageable.

Tammy had just completed her second brain surgery, and was continuing a nearly-ongoing regimen of chesotherapies and other

Someone introduced us to Patient Advocate Foundation (PAF). who swiftly came in and offered us financial support to cover treatments. some of the weight 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.

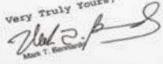
Sadly, Tammy lost her battle with brain cancer in 2012. When she was diagnosed in 2000, she was expected to live for 9 sontha, with a possible 18 month survival. Our daughters were 2 years old and 8 months old at the time of her diagnosis.

We prayed and sought the best possible medical help available. With the support of top-notch medical professionals - and in no small part assisted by your financial support - Taxony lived for 12 years after her diagnosis. Our daughters were able to be raised into their middle-school years by their mother who

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

Attached please find a check. It is a small gift, but my hope is that it can be a check. It is a small gift, but my hope is that it can be joined with the gifts of others to bring acces help and hope to someone at the state of others. and hope to someone struggling during a challenging time. Thank you so much for all you did for our family, and for all you do for everyone also you

do for everyone else you serve.



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

256k+ INDIVIDUAL GRANT PAYMENTS PROCESSED



WHEN PAF PATIENTS WERE ASKED ...

63%

experienced financial hardship in the past year due to the costs of their medical care

(PAF 2018 Cost-of-Care Survey)

reported that out-of-pocket medical costs were a significant barrier to achieving healthcare goals

(PAF 2019 Retrospective Survey)

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 Bennardo family

HOW WE HELP HOW WE HELP





Over 44k educational materials mailed, distributed via outreach or through case management activities.



tiny.cc/resourcelibrary

Received the Bronze medal award in the 22nd Annual Digital Health Awards®

INCREASE

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.

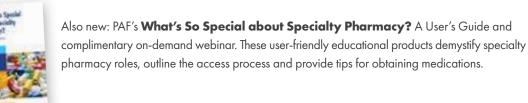
The Education Resource Library contains PAF's entire catalogue of content in an easily accessible, searchable format, crossing category filters for 13 topics, 4 content types and 2 languages. In 2020, 7 new, 32 updated and 9 translated publications were released, along with 28 webinars. A video introduction 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

in average daily use compared to 2019

TOTAL SEARCHES completed by users provided to users





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. Corter

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

Migraine Matters

Matters of the Heart (MOH), PAF's selfdirected 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





2020 Data Highlights of PAF's Online Subscriber **Community Engagement**

growth in online subscriber communities over 2019

individual communications delivered to our subscribers

increase in subscriber engagement rate compared to 2019

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



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/

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

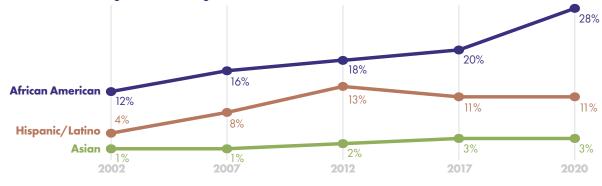
Health Equity & Community Engagement

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 .5% as American Indian/Alaska Native.

PAF's Progress in Reaching Underserved Patients





tiny.cc/smhcast

PAF'S HEALTH EQUITY WORK IS NOT A MOMENT. IT'S A PHILOSOPHY.

Many of PAF's activities are based on strategic partnerships with other organization 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 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.





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

Reducing Employee Risk: COVID-19,
Tobacco Use and Smoke-free Environments.

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.



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



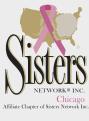
Through SelfMade Health
Network, collaborated
with the Memphis Breast
Care Consortium for video
production to educate Black
women on what it means to
have a breast cancer diagnosis

On the ground collaborative partners in 2020 included:









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."

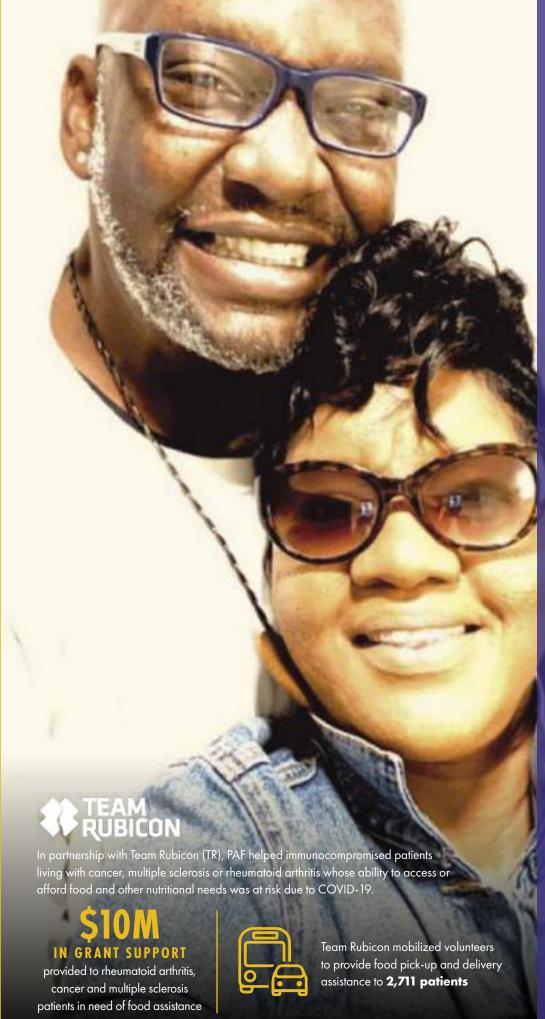
– LaQuita, Ricky's Wife

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-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...

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

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

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

2020 Case Management Service by the Numbers

CONTACTS MADE WITH OR ON BEHALF

OF A PATIENT TO RESOLVE THEIR CASE

DAY AVERAGE TO WORK A CASE

TOTAL CASE COUNT

HOW PATIENTS FIND PAF CASE MANAGEMENT SERVICES







Organization or Representative Representative



Media and Outreach



Cases referred to PAF by other nonprofit organizations

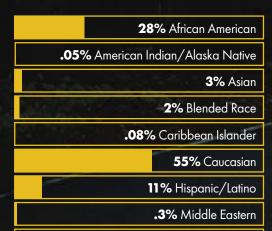


Patient previously served by PAF

Organizations

131% increase in referrals from friends and family

ETHNICITY



.2% Native Hawaiian/Other Pacific Islander

INSURANCE STATUS

83% Insured

17% Uninsured

INCOME

	47% < \$23,999
	28% \$24,000 - \$47,999
	12% \$48,000 - \$71,999
	6% \$72,000 - \$95,999
11.19.1	3% \$96,000 - \$119,999
	5% \$120,000 or More

AGE

- A	3% Birth to 18
100	19% 19 to 35
	30% 36 to 55
	41% 56 to 75
	7 % Over 75

45% increase in the number of uninsured patients

EMPLOYMENT

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

11% increase in the Unemployed

CASE MANAGEMENT STAFF EXPERIENCE



have some type of post-high

speak Spanish

ES



years of combined healthcare experience prior

to coming to PAF

299 of those are navigation or case management experience

sort of job-related training



and core services

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

TOP 10 DIAGNOSIS CATEGORIES SERVED BY CASE MANAGEMENT



Diseases

Diseases



Diseases











System

Conditions

Conditions



Patient Advocate Foundation CPR SERVICE BY THE NUMBERS







16% increase in the arant bayment total





Patients Served by CPR Since 2004

9 NEW CPR DISEASE FUNDS LAUNCHED IN 2020

- Acromegaly
- COVID-19
- Gaucher Disease
- Hepatocellular Carcinoma
- Metastatic
- Spinal Muscular

Pancreatic

Cancer

Melanoma • Hemophilia

Joyce Graves & Thyroid Eye Diseases

"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!"

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/3jC2zqn

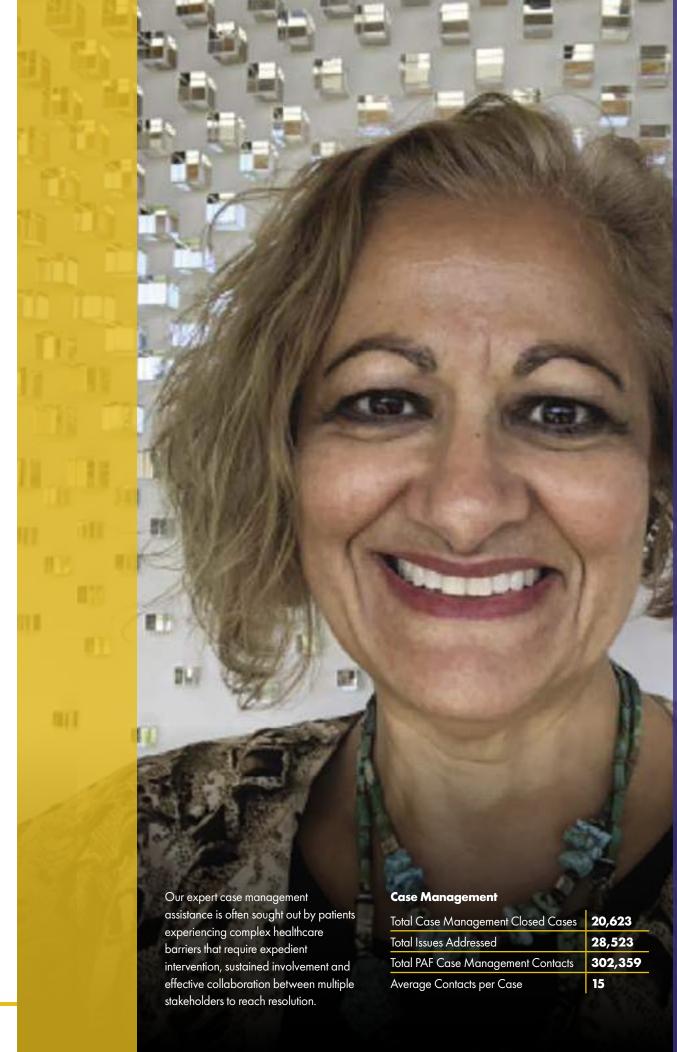


Engaging with Insurers: Appealing a Denial, available in print and online, focuses on patients' rights, effective communication, self-advocacy and navigation through health insurance denials.

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



WHEN PAF PATIENTS
WERE ASKED...

34%

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)

2020 DATA POINTS:

Distinct Patient Diagnoses:

629

Of those diagnosed:

246

were Distinct Rare Diseases

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.



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

42% stated "staying healthy" was their areatest 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

furlough

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

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

illnesses

64% of patients

the way they

accessed care

stated they changed

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

47% reduced hours

12% experienced a

10% were laid off or lost their employment

Healthcare Access COVID-19-related **Challenges**

Accessing Care

53% reported 55% said they had healthcare access challenges related to the treatment of non-

challenaes in keeping or receiving appointments for specialty care doctors

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

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

40% reported

being "extremely

received during

a telehealth visit

satisfied" with care

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

45% reported

keeping or receiving

challenaes in

appointments

physician

for primary care

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

42% 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.

78% new conference opportunities **ABSTRACTS**

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)

PUBLISHED JOURNAL ARTICLES

Examples:

"Mitigating Cost of Care Conversations." HIV Specialist, March 2020. nxtbook.com/ygsreprints/AAHIVM/G116663_ AAHIVM 032020/index.php

"A Pilot Study of a Comprehensive Financial Navigation Program in Patients with Cancer and Caregivers." Journal of the National Comprehensive Cancer Network, Oct. 2020. jnccn.org/view/journals/jnccn/18/10/ article-p1366.xml

RESEARCH **PRESENTATIONS**

Examples:

"Evolving the role of Non-profit Organizations in Addressing Social Determinants of Health." Rapid fire presentation. 2020 AcademyHealth National Health Policy Conference, Washington, D.C. Feb. 10-11, 2020.

"Ensuring nutritional access in the time of COVID-19: A multi-organizational approach providing support to immunocompromised individuals struggling with food insecurity." 2020 APHA Annual Meeting, San Francisco CA, Oct. 26-29, 2020.

RESEARCH ACTIVITIES AND PARTNERSHIPS

Examples of Data Analysis and Dissemination Partnerships

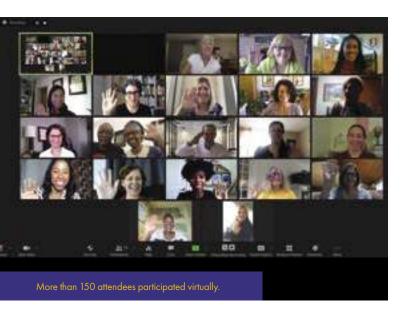
- University of North Carolina at Chapel Hill Examining the impact of cancer diagnosis on employment and the role of the employers in supporting newly diagnosed cancer patients.
- University of Alabama at Birmingham/MD Anderson Medical Center Comprehensive review of PAF's COVID-19 survey data.

Academic & Non-Profit Grant Funded Research

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

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

SPECIAL EVENTS
SPECIAL EVENTS



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



PAF staff members, Becki, Chanda, Tetring out for the virtual race. Crawlin'Crab

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

Promise of Hope

\$214,000 raised

30 scholarships funded (increased from 25)

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

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**

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 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



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

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.



"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



tiny.cc/parkerprofile

FINANCIAL STATEMENTS

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.

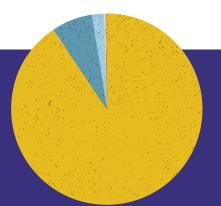
SUMMARY OF TOTAL PATIENT IMPACT IN FISCAL YEAR 2019/20

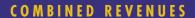
Total Patient Cases	188,696	
Total Case Management Cases	21,231	
Total Co-Pay Relief Cases	72,906	
Total Financial Support Programs Cases	67,637	
PAF COVID Financial Support	14,431	
Total Patient Services Email Helpline Sessions	12,491	
Total Patient Services Case Contacts	1,301,755	

SUMMARY OF CASE MANAGEMENT IMPACT IN FISCAL YEAR 2019/20

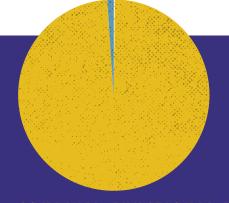
Total PAF Case Management Case Count	21,386*
Unique Case Management Patient Issues	36,240
Total PAF Case Management Contacts	334,734
Average Contacts per Case	15.7

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





- **92%** Program Grants \$278,137,670
- **6%** Program Administration \$18,618,857
- **1%** Interest \$3,882,221
- **.13%** Gifts & Contributions \$383,937
- **.06%** Event Revenue \$193,770
- **.01%** In-Kind Service \$36,924



COMBINED FUNCTIONAL EXPENSES

- **98%** Program Services \$257,702,676
- 1% Management & General \$2,860,826
- .41% Fundraising \$1,085,844

TOTAL \$261,649,346

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

		2020		2019
ASSETS				
Current assets				
General operating cash and cash equivalents	\$	34,643,003	\$	28,077,632
Restricted cash and cash equivalents		172,931,062		250,800,565
Unconditional promises to give		14,086,492		17,254,062
Accounts receivable Interest receivable		1,611,627		538,498
Due from National Patient Advocate Foundation		266,096 41,713		- 18,43 <i>7</i>
Investments and cash equivalents		127,186,163		2,078,900
Inventories		55,002		42,269
Prepaid expenses		471,457		412,217
Total current assets	_	351,292,615		299,222,580
Property and equipment, net		3,919,924		4,321,760
Other assets		50,331		50,331
	\$ _	355,262,870	\$	303,594,671
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	т	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		4,148,581		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

FINANCIAL STATEMENTS

Patient Advocate Foundation Statements of Activities Years Ended June 30, 2019 and 2020

		2020			2019	
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
OPERATING REVENUES Contributions:						
Grants	\$ 3,838,516	\$ 274,299,154	\$ 278,137,670	\$ 3,759,260	\$217,776,219	\$ 221,535,479
Private and public donations	258,937	•	258,937	165,787	•	165,787
Donated services and materials	36,924	•	36,924	35,314	•	35,314
Program administration	18,618,857	•	18,618,857	16,996,013	•	16,996,013
Patient Congress	20,000	•	70,000	80,000	•	80,000
Promise of Hope	123,770	•	123,770	141,650	•	141,650
Patient Action Council	125,000	•	125,000	75,000	•	75,000
Investment return	3,882,221	•	3,882,221	5,559,850	•	5,559,850
Net assets released from restrictions:						
Satistaction of program restrictions	238,734,798	(238,734,798)	1	235,446,577	(235,446,577)	•
Total revenues, gains and other support	265,689,023	35,564,356	301,253,379	262,259,451	(17,670,358)	244,589,093
OPERATING EXPENSES						
Program services:						
Patient/educational services	5,575,996	•	5,575,996	5,867,102	•	5,867,102
Financial aid programs	246,082,505	•	246,082,505	242,788,385	•	242,788,385
Service contracts	6,044,175	•	6,044,175	5,234,955	•	5,234,955
Supporting services:						
Management and general	2,860,826	•	2,860,826	2,746,021	•	2,746,021
Fundraising	1,085,844	1	1,085,844	1,138,723	'	1,138,723
Total expenses	261,649,346	1	261,649,346	257,775,186	1	257,775,186
Change in net assets from operations	4,039,677	35,564,356	39,604,033	4,484,265	(17,670,358)	(13,186,093)
OTHER NONOPERATING CHANGES Postretirement benefit charges other than periodic cost	(942,934)	,	(942,934)	(20,085)	,	(689,077)
Change in net assets	3,096,743	35,564,356	38,661,099	3,795,188	(17,670,358)	(13,875,170)
Net assets, beginning of year	15,351,653	264,038,071	279,389,724	11,556,465	281,708,429	293,264,894
Net assets, end of year	\$ 18,448,396	\$ 299,602,427	\$318,050,823	\$ 15,351,653	\$ 264,038,071	\$ 279,389,724

Supporters

Big Woody's Bar and Grill 3 Bowls of Color Eddie and Cindy Black AbbVie AcademyHealth David Blalock, Jr. Ace Peninsula Hardware Marcy Blanchard Jeffrey and Jill Blinder Ace Peninsula Hardware Meagan and Charley Bocklet Newport News Boehringer Ingelheim Bryan Agnello Kathy Booher Maria Ainbinder Dennis Boteler Susan and William Allcox Nicole Braccio David Allen Jill Bradley **ALS** Association Erin Bradshaw AmazonSmile Brandi Ledford Beauty American Cancer Society Cheryl Brazie American Lazer Arts, LLC Breakaway From Cancer American Oncology Network, LLC Breeger Media Group America's Health Insurance Plans Jennifer and Fred Brewster Amgen Lee Newie Brinker Amgen Foundation Bristol-Myers Squibb Kadhambari Anbalagan Bristol-Myers Squibb Foundation David and Caitlin Anderson Debbie Bristow Eric Anderson Allison Brooks Marbrico Anderson Cecelia Brosnahan Carolyn Andrews Ambria Brown Alena Androsenka Angelia Brown Deborah Andrus Benton Brown Tracy Andrus Emily and Richard Brown Arby's Restaurant Craig Brownlie Mike and Kelly Archuleta Buggy Bathe Auto Wash, AstraZeneca Lube & Detail Shoppe AT&T Employee Giving Campaign **Emily Bullock** Shonta Atkinson-Chambers Beth Burnett Atlantic Bay Mortgage Group Tiffany Busch Jeanine and Ken Baggett Angela Butler Alan and Valerie Balch C.D. West & Company Real Estate Glen Balch Edna Caldwell Barbara Baldridge Dwana Calhoun **Baltimore** Orioles Canopy Washington DC The Wharf Lawrence Banion Steven Bank John and Michelle Cardoso Roger Banks Saundria Cardwood **Hugh Barlow** Peggy Carroll Luvenia Barnes Rebecca Carroll Sheryl Barnes Cynthia Carter Teresa Barrett John and Jeannette Carter Eric and Lisa Bartelli Lisa Cassanova Barbara Basabilbaso Bryan and Fran Castellow Daniel Basnight Nataly Castro Camille Bates Vincent and Susan Catlin Christie and Charlie Bates Katherine Center Dave and Jenn Bates Centers for Disease Control Brian and Timorah Beales and Prevention Jackie Beard Gerard Champagne Dakota Rosa Beasley Chase Begin Again Foundation **Brad Chattillion** Mark Bellehumeur Chevron Karen Bender Nick Chrismon Richard Bennett Beth Cicero

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