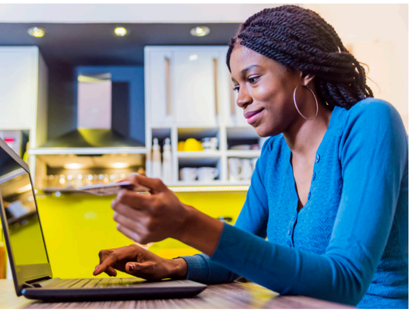
ANNUAL REPORT 2019

PATIENT SERVICES
INCORPORATED

Table of Contents



2019 Board and Executive Leadership

Board of Directors

Gary W. Cross
Chairman of the Board
Resigned in May 2020

Mitch Mula
Vice Chair

Russell E. Phillips Jr.,
CPA, CVA, MAFF
Treasurer

Brian Landry
Secretary

Terrie L. Glass, LCSW
Board Member

Brian L. Fink, JD
Board Member

PSI Board of Directors


Gary W. Cross


Mitch Mula


Russell E. Phillips, Jr.


Brian Landry


Terrie L. Glass


Brian L. Fink

Executive Leadership

Art Wood
CEO
Retired in July 2020

Gwen Cooper
CEO
Effective June 2020

Michael Herbert, MBA
Vice President

PSI Executive Leadership


Art Wood


Gwen Cooper


Michael Herbert

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Allen Murfee
Allison Furniss
Amanda Herbert
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Amicus Therapeutics, Inc.
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Commission for Children with Special Health Care Needs
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Edmond P. Herbert
Ethical Factor, RX
Gary and Nadene Carlson
Genzyme Corporation
Grifols USA, LLC
H.M. and Brenda Womack
Harolyn and Elmer Thogersen
Helen R. Wilson
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Hemophilia of Georgia, Inc.
Hemophilia Outreach Center
Indiana Hemophilia & Thrombosis Center, Inc.
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Lauren Raines
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Retrophin
Robert Glasser
Sheila Arquette
Shire Human Genetic Therapies, Inc.
South Carolina Department of Health and Environmental Control
South Carolina Department of Health and Human Services
St Elizabeth Hospital Volunteer Auxillary
Sue M. Cole
Susan Elpers
The Hemophilia Alliance Foundation
Thomas and Diane Deasy
University of Pennsylvania Medical Center
US HAE Association, Inc.
Vanda Pharmaceuticals, Inc.
Virginia Department of Health
Vivian and Edward Zuehlke
Volker Uhrig
Wawa Foundation
Weston Smith

Ways to Support PSI

Your Tax-Deductible Donation

For 30 years, PSI has been fortunate to receive financial support from thousands of donors who simply want to help chronically ill patients afford the cost of their treatment. In 2019, PSI received its eleventh consecutive 4-Star Charity Navigator Rating for being a leading symbol of transparency and accountability. This is Charity Navigator's highest possible rating! Only 1% of the charities evaluated have received this rating indicating that PSI outperforms most other charities in America. In addition to our high rating with Charity Navigator, PSI is a Platinum charity with GuideStar. PSI extends a heartfelt thank you to the generous donors who gave to PSI in 2019 recognized within this report. It is our hope that others will follow your lead and support our mission in the upcoming years. To provide support, please visit the "Donate" section of our website, **www.patientservicesinc.org**.

CHARITY NAVIGATOR
★★★★
Four Star Charity

GUIDESTAR®
PLATINUM
PARTICIPANT

Ways to Give

Every donation counts! Thank you to our generous donors for helping us restore hope and health to over 13,000 patients in need in 2019. By removing the financial burden associated with chronic illness, we allow patients to focus on what's most important - time connecting with family and friends. Time creating memories.

Donate online: PSI welcomes donations of all sizes. Your generous gift will help patients pay for expensive health insurance premiums, copayments, travel services, as well as infusion and nursing services. These are all costs that patients would not be able to afford on their own. To make a secure online donation, visit https://www.patientservicesinc.org/donate.

Donate by mail: To donate by mail, simply mail your check to Patient Services, Inc. at P.O. Box 5930, Midlothian, VA 23112.

Make a donation in someone's name: An Honorary or Memorial Donation offers a thoughtful way to honor the memory of a loved one or commemorate important occasions while supporting PSI. Your generous donation will directly support PSI's patient assistance, educational and advocacy programs, restoring hope and health to someone in need. Visit **https://www.patientservicesinc.org/donate** to designate your donation to the area of greatest need or program of your choice. Contact **PSIDevelopment@uneedpsi.org** for more details.

Thank You for Your Support!

On behalf of the PSI Board of Directors and Staff, we would like to express our sincere appreciation for your generous contributions made in 2019. Because of you, PSI provided $56.4 million in direct patient assistance to over 13,000 chronically ill patients in 2019. Thank you for restoring hope and health to the rare disease community!

Message from the CEO

2019 was a year of significant transition for PSI.

First, I announced my intent to retire, triggering a national search for my replacement that started in the later part of 2019. To ensure a smooth transition, we initiated an intensive training program for our General Manager, Mike Herbert to take on more of the day to day responsibilities. Please join me in congratulating Mike in his new role as PSI's Vice President.

Our new CEO, Gwen Cooper began her tenure with PSI shortly before the printing of our 2019 Annual Report. I know you'll join me in wishing her much success during her tenure with PSI.

The second significant development occurred right before the New Year. Long supporters know the mission of providing financial assistance to patients continued to be under attack from the government and media. PSI has been fighting to protect the non-profit patient assistance model, and much of 2019 was spent addressing the ongoing regulatory concerns by the Office of Inspector General (OIG) and Department of Justice (DOJ). To resolve these concerns PSI and three of our sister foundations agreed to a settlement with the government at the end of the year. This new blueprint for operating our public assistance funds surely helps pave the way for our new CEO to have a roadmap for PSI's future.

On the Program Development side, our team navigated changing dynamics in the donation request and commitment process. More and more donors have moved to an online grant request process, sometimes that means less "one on one" conversations and more creative writing grant requests to showcase the important need in serving patients with chronic and rare diseases. Even with all of the uncertainty during the budget year in confirming donations to support our disease funds, the team worked hard to meet and exceed our donation targets. I'm thrilled to report that they were successful, and we look forward to 2020 with renewed enthusiasm and using our grant writing expertise in the future to secure needed donations.

Our Government Relations Team continued their efforts to introduce legislation that would protect the non-profit patient assistance model as well as address some of the challenges for patients to access treatments. PSI continued to be the leader among all of the other patient assistance foundations and patient advocacy groups in proactively seeking solutions.

Attendance at yearly conferences provided visibility for PSI and meaningful interactions with current donors. One of the significant things that was noted was the constant discussion at conferences about new therapies such as gene therapies on the horizon which will provide potential cures for many disease areas! This was great news; but because we know these treatments will be extremely expensive, the need for patient assistance for patients to continue therapy will be ever more important.

All in all, it was the year that provided the foundation for the next stage in PSI's growth and development under new leadership. I feel proud that PSI continues to do mission critical work that provides hope and healing to thousands of patients and their families each year. We all look forward to a bright future!

Art Wood
CEO

Government Relations

The role of the Government Relations Team at Patient Services Incorporated (PSI) is to advocate for the best public policy outcomes for the rare disease and chronically ill communities our organization serves. The Government Relations team advances legislation to protect access to nonprofit patient assistance programs (like PSI) and limit the financial burden on patients and their families. Our team builds partnerships with policymakers, patient advocacy organizations and the patients themselves. We work with state health agencies to reduce the health care cost burden while enhancing access to care for patients. Finally, we educate our patients on legislation and agency rules as well as trends in health care public policy.

Change was the theme in 2019 for Government Relations. The PSI Government Relations team welcomed the addition of Mr. Nathan Thomson. Nathan joined the team as the Associate for Government Relations with a background in policy. Nathan brings to the team a doggedness for knowledge and a passion to help patients. Nathan has become a welcome member of the PSI community. He has not skipped a beat, fitting right in with team members and building relationships with state advocates from all over and representing PSI at events.

This past April, PSI again hosted the Coverage & Access Forum alongside PSI Advocacy Day. Our team brought together 50 patient advocates, public policy specialists and influencers for a day of education on a variety of public policy topics involving issues affecting public and private health insurance coverage. For example, PSI hosted panels discussing state advocacy efforts to limit the Copayment Accumulator; updates on Medicaid Part D Rules; and legislation involving the updating of emergency treatment protocols. The next day, PSI then took over 60 patient advocates to Capitol Hill to meet with legislators and advocate for the importance of patient assistance programs and specifically to modify the Centers for Medicaid and Medicaid (CMS) Rule on Third Party Health Insurance Premium Assistance.

PSI partnered with organizations such as Good Days and the coalition United for Charitable Assistance to host the Chronic Disease Day Briefing on Capitol Hill in July. PSI patient advocates Lisa Wright and Jordan Martin joined with Senator Kevin Cramer (R-ND) to call attention to patients fighting chronic illnesses while also discussing the importance of patient assistance. Approximately 100 Capitol Hill staff members attended this briefing and met with our advocates to hear their struggle of overcoming adversity.

The PSI Government Relations Team attended several state advocacy days across the United States working with patient advocates in North Carolina, South Carolina, Kentucky, and Virginia to promote state legislation limiting copayment accumulators and attacks on health insurance coverage. PSI attended both the Association of Maternal and Child Health Programs Meeting (AMCHP) and the National Conference of State Legislators meetings to promote our state assistance program model.

PSI looks forward to continuing to lead on Capitol Hill and in state legislatures to preserve the patient assistance model while expanding affordable access to rare disease and chronically ill patients.

James Romano, MPA, MBA
Director of Government Relations


L-R: Jordan Martin, Lisa Wright, Congressman Anthony Delgado (D-NY), Justin Wilson and James Romano.


L-R: Michael Bradley, Art Wood, Congressman Hank Johnson (D-GA), Christ Draft and Tony Castaldo.


L-R: Justin Wilson, Lisa Wright and Jordan Martin on Chronic Disease Day.

I was first intrigued by the mission when I started working for PSI. It's admirable and everyone here strives to fulfill that mission to the best of their ability. The desire to assist others is contagious, and I am grateful that I get to be a part of what PSI does.

Alyssa G.
Patient Services Representative

The wonderful thing about working with PSI patients is that on every call there is some form of inspiration. Whether that be a newly diagnosed patient with the courage to figure out their next steps or a patient who has had their condition since birth with the will to keep fighting. There is strength in every tear drop and hope in every thank you and I am in awe of them all!

Amy J.
Patient Access Specialist

On the front lines answering the call. Over 56,000 calls. 15 Representatives.

It is refreshing to know that I work for a company that genuinely cares for the well-being of the patients that we assist. Not a robotic company to provide general information but a friendly voice behind every, "Thank you for calling PSI, how can I help you?". Providing information with a smile and an ear to listen when needed. Understanding healthcare costs can be expensive, it gives me joy that we are able to provide assistance to offset some of those costs that patients face. I love coming to work for a family-oriented business who strives for excellence and demands nothing less. Glad to be in the service of giving back to those in need.

Tracy S.
Program Manager

Before joining the PSI family, I was not aware of the large population of people living with rare diseases. I handle a variety of calls each day, the ones that are most rewarding are the patients who I'm able to offer assistance. Many of the patients I speak with have explored all other resources and are ecstatic to find that we can offer assistance. The job I perform each day reminds me of one of my favorite scriptures "to whom much is given much is required" and I take comfort in knowing that I am fulfilling my purpose by giving my patients the opportunity to receive the assistance they desperately need.

Sharon JF.
Patient Services Representative

Patient Programs Data

154,773
NUMBER OF CLAIMS PAID

14,476
PATIENTS ASSISTED

2
AVERAGE HOUSEHOLD SIZE

64
AVERAGE PATIENT AGE

$35,916
AVERAGE HOUSEHOLD INCOME

14
AVERAGE MONTHS OF ASSISTANCE

$4,200
AVERAGE AMOUNT PER PATIENT ASSISTED, 12% OF PATIENTS' INCOME

4.5 Minutes
AVERAGE TALK TIME

IT Department

The only thing that is constant is change.

There has never been a truer statement in Information Technology. Today's iPhone quickly becomes obsolete as soon as you walk out of the store, and the same can be said of technology processes. However, at Patient Services, Inc. we are constantly evolving and adapting to remain at the cutting edge of technology to provide the best support for our patients and providers. Below are some of the initiatives we've worked on in 2019 and will be working on into 2020.

2019 Initiatives

- Simplified display screens to help ease navigation on both Referral and Patient Portals
- Streamlined documents tab to help patients better locate documents within the Patient Portal
- Made information flow more efficiently with the transitions from "snail mail" to email
- Limiting views for providers between private and public insurance patients

2020 Initiatives

- Expanding call options for patients who inquire about their applications status and account needs
- Enhancing our main website to allow for greater ease in navigation
- Modifying our benefit pharmacy process, so patients can have less hassle when filling their medications

A.C.C.E.S.S.® Program

PSI- A.C.C.E.S.S. closed 2019 with 34 active disability cases. Our attorneys appeared at 32 hearings across the country during the past year and we resolved a total of 39 claims. 70% of our clients whose claims went to adjudication were awarded benefits, compared with the national average for all applicants of just 36%.

Our current caseload by disease state communities that we serve:

Bleeding Disorders	**57%**
Immune Deficiency	**19%**
Alpha 1 Antitrypsin Deficiency	**24%**

A.C.C.E.S.S. has offered legal representation for people pursuing Social Security Disability (SSD) and Supplemental Security Income (SSI) claims since 1989. Since we joined Patient Services, Inc. in 2009, we have represented 945 clients and appeared at 511 hearings.

With the incidence of disability decreasing in certain populations due to advances in treatment, we continue to focus on counseling our clients about workplace issues and A.C.C.E.S.S. to health care coverage.

Since launching in May of 2013, the PSI- A.C.C.E.S.S. Legal Support Hotline has counseled more than 1,000 callers with a variety legal questions and issues. The hotline provides expanded counseling to our core disease state communities on a range of issues related to disability, accommodations at school or work, medical leave and changes in health insurance.

In November 2019, our long-time A.C.C.E.S.S. attorney, William Leach, retired after 24 years of service to our chronically ill communities. His depth of knowledge, expertise and passion to be of service will be greatly missed. However, going forward, we will continue our dedication to helping find solutions to the social and economic problems that confront families facing chronic conditions.

Katherine Crowe
Senior Disability Specialist

Finance Report

Patient Services, Inc. had a financially successful 2019, despite operational and regulatory challenges. The Balance Sheet remains strong, with sufficient reserves to meet all our program obligations. Revenues of over $70 million met expectations and were comparable to 2019 results. We remain grateful for the continued generous support from our donors, without whom we could not fulfill our mission.

PSI provided program services totaling nearly $59 million in 2019, including $56.4 million of direct financial assistance payments to patients. Most of this assistance went to help people with their insurance premiums and drug copayments, but also included payments for travel, infusion and nursing services, and ancillary needs. PSI also provides insurance case management and eligibility determination services for many patients.

Approximately 92% of the organization's total functional expenses were spent on program services, primarily copayment and insurance premium assistance. Operational efficiency continued to improve, with total administrative costs reduced by 11% compared to the prior year.

Our financial statements and programs are audited annually by an independent accounting firm. Once again, PSI received a favorable unqualified audit opinion in 2019. A copy of our 2019 audited financial statements and associated communications can be found on our website at **https://www.patientservicesinc.org/who-we-are/annual-report**. The financial information below provides an overview of our financial performance for 2019.

Daniel Wise
Director of Finance

Summary Statement of Financial Position
December 31, 2019 and 2018

ASSETS	**2019**	**2018**
Current Assets	$103,332,664	$100,911,034
Property and Equipment	2,016,030	2,115,831
Other Assets	7,921,933	6,928,276
Total Assets	$113,270,627	$109,955,141
LIABILITIES AND NET ASSETS		
Current Liabilities	$3,900,981	$828,111
Net Assets without donor restrictions	14,146,418	16,647,070
Net Assets with donor restrictions	95,223,228	92,479,960
Total Liabilities and Net Assets	**$113,270,627**	**$109,955,141**

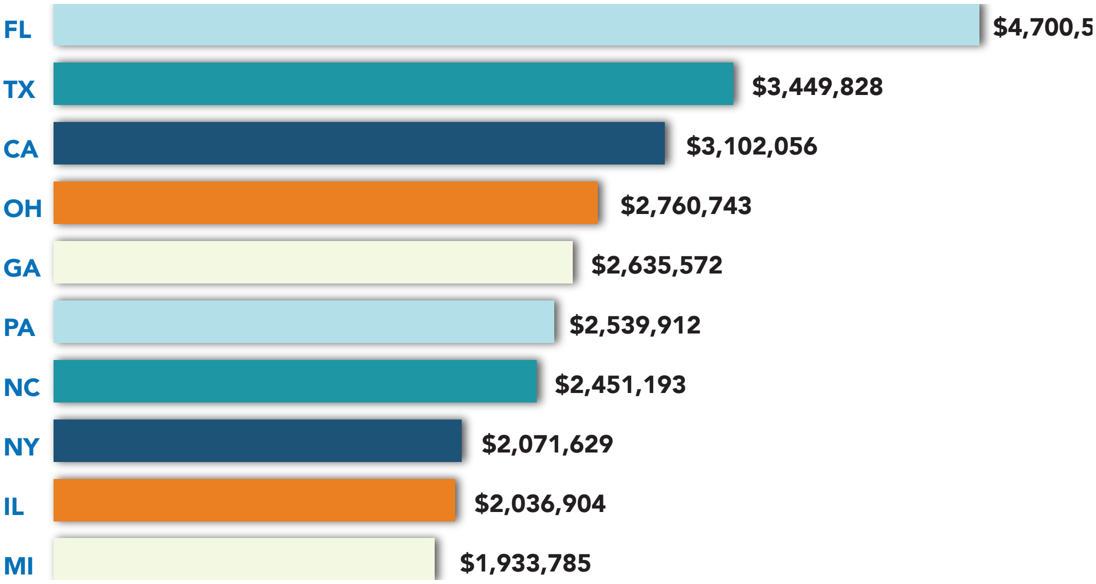
Statement of Activities (2019 and 2018)

	Without Restrictions	With Restrictions	Total 2019	Total 2018
REVENUES AND OTHER SUPPORT				
Contributions and contract fees	$6,773,324	$62,086,543	$68,859,867	$71,827,550
Fees for contracted services	–	–	–	1,482,409
Interest income	695,074	–	695,074	236,733
Miscellaneous income	4,326	–	4,326	57,442
Gain (Loss) on Investments	869,274	–	869,274	(392,180)
Net assets released from restrictions	56,387,811	(56,387,811)	–	–
Total revenues and other support	**64,729,809**	**5,698,732**	**70,428,541**	**71,729,545**
EXPENSES AND LOSSES				
Program services	58,725,645	–	58,725,645	74,292,257
Fundraising	661,739	–	661,739	903,932
Management and general	4,672,471	–	4,672,471	5,242,575
Total functional expenses	64,059,855	–	64,059,855	80,438,764
Uncollectible pledge expense	170,606	2,955,464	3,126,070	3,549,006
Loss from legal settlement	3,000,000	–	3,000,000	–
Total expenses and losses	**67,230,461**	**2,955,464**	**70,185,925**	**83,987,770**
Change in net assets	**(2,500,652)**	**2,743,268**	**242,616**	**(12,258,225)**
NET ASSETS				
Beginning of year	16,647,070	92,479,960	109,127,030	121,385,255
Ending	**$14,146,418**	**$95,223,228**	**$109,369,646**	**$109,127,030**

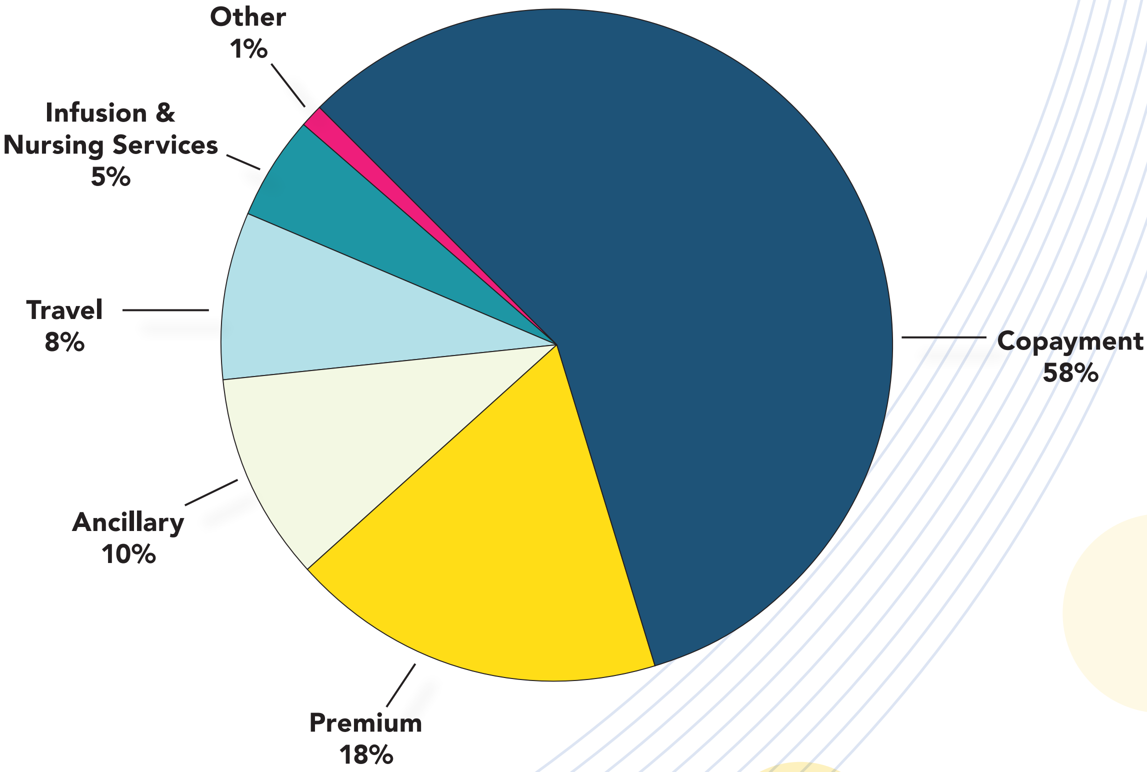
The financial information reported here is for PSI only and does not contain consolidated subsidiary information. A complete copy of the Consolidated Financial Statements with a certified report from our independent auditor, Keiter, is available by calling 1-800-366-7441 or by visiting our website, www.patientservicesing.org.

Financials *(Year ended December 31, 2019)*

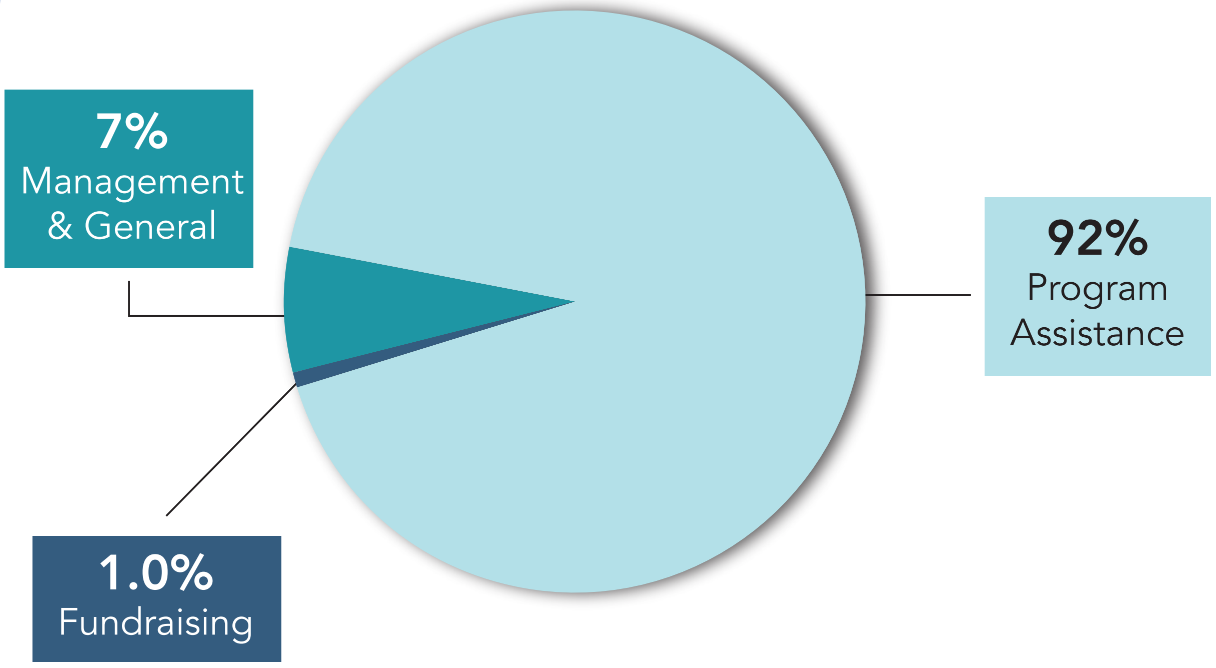
Financial Assistance by Top 10 States



Percentage of Patients Enrolled by Assistance Type – 2019



Functional Expense



Over 92% of the organization’s total functional expenses were spent on program services for patients.

Treating aHUS: This Disease Has Forever Changed Me

"The first year of my illness cost my Insurance company $1 million. My infusion, every 14 days, costs my insurance company $28,000. Yes, that number is correct."

With no cure, treatment was the only course of action for Elaine, who had been diagnosed with atypical hemolytic uremic syndrome (aHUS).

This Rare disease is estimated at only 2 cases per 1,000,000 of population in the United States. More than half of those diagnosed with aHUS are children.

The condition can be life threatening. But as we just read, the cost of treatment, can be as well.

What Is Atypical Hemolytic Uremic Syndrome?

According to the **National Center for Advancing Translational Sciences,** atypical hemolytic uremic syndrome (aHUS) is a disease that causes abnormal blood clots to form in small blood vessels in the kidneys. These clots can cause serious medical problems if they restrict or block blood flow, including hemolytic anemia, thrombocytopenia, and kidney failure. It can occur at any age and is often caused by a combination of environmental and genetic factors.

To more simply define what is occurring with atypical HUS, ahusallianceaction.org writes, "aHUS patients have symptoms of anemia (extreme tiredness) and fluid buildup as an outcome of the kidneys not working. Medical professionals use medication, therapy, surgery, and other treatments to help lessen the symptoms and effects of a disease."

How Is Atypical Hemolytic Uremic Syndrome Diagnosed?

The Atypical HUS Foundation, which exists to provide information, insight, and resources for the aHUS community in America and the world, describe diagnosis for aHUS as,

"Most of the time, atypical HUS does not present with initial severe symptoms. The initial onset will most likely appear to be flu like, with lethargic behavior, pale color and a loss of appetite. It has been our experience that adult hospitals may often send the patient home with a flu diagnosis, while children's hospitals may do a blood draw and conduct basic tests, such as Hemoglobin, Hematocrit, white blood cell counts, and platelet counts."

The costs of having a rare disease doesn't begin with treatment.

What's Happening to Me?

In her own words, Elaine, a patient of Patient Services Inc., describes her journey to diagnosis of atypical hemolytic uremic syndrome:

"I was 62 years old when I began to feel unwell. I had led a very active life, raising a family, working, exercising and conscious healthy eating. I did everything right!

When 2013 came along, I struggled with pain moving around my body, often a different place every day and mostly in my joints. I was also overly tired. In January of 2014, I felt as if I had a flu. I saw my doctor for a checkup and was told I was anemic and had high blood pressure. I was very surprised, but the doctor said It was probably just my age.

A week later I went to the ER in the evening because I was having difficulty breathing. The ER sent me home with the knowledge that I had a very slight elevation of my BUN and gave me Lasix to get rid of fluid which they thought was my problem. I did as they said and made an appointment with my GP in 10 days. Nine days later I went back to the ER because my doctor was unable to see me.

I was in kidney failure and was admitted. I remember almost nothing of my first 3 days. After 30 days in the hospital, I had a kidney biopsy and a cath placed in my chest. I then began dialysis and plasma apheresis."

Can Anyone Help Me?

At this point of Elaine's journey, atypical hemolytic uremic syndrome had become a reality. And with this, treatment varies, as each case is so uniquely different. It is during this time where atypical HUS patients are much more likely to develop complications such as:

- Recurrence of initial symptoms
- Kidney failure
- Seizures, neurological problems or other multi-organ involvement.
- No response to supportive treatments
- Return of atypical HUS even after a kidney transplant occurs
- Severe hypertension (high blood pressure)

According to the NIH, there is but one FDA approved treatment for atypical HUS patients, and as we read previously, the cost is astronomic.

When the FDA-approved treatment became an option for Elaine, she would have to wait another 2 weeks after she had been given a Meningococcal vaccine. Yet, by that time Elaine tells us, her kidneys were long gone.

It would be 22 months of dialysis before she was able to get a transplant.

Being Diagnosed with Atypical HUS Has Forever Changed Me

Elaine continues as she shares how this rare disease has forever changed her life.

"I had started a new job in 2014. I was having difficulty remembering codes that I need to enter into the computer which was symptomatic of my illness. I was not able to go back to work and still am not able to work. I now get infusion every 14 days.

I am immune deficient and have difficulty fighting illness. I tire easily and if under stress, I shake uncontrollably. This disease has forever changed my life. I have little energy to expend outside of daily living."

Alongside Elaine and her family, we continue to hope for breakthroughs to treat and even cure her condition. A diagnosis shouldn't mean life or death due to the enormous costs of treatment. It shouldn't even be given a seat at the table when discussing what's next.

But sadly, it is. And we at PSI want, if at all possible, to be sitting right there next to you, holding your hand, and telling you that together, we can do this.

You are not alone and therefore do not need to face this alone.

"My husband is hoping to retire soon, at 68. This has been a blow to our finances, but we are extremely grateful for the financial help that PSI has generously given us." says Elaine.

And we, Elaine, are extremely grateful to be sitting right next to you.

Have You Been Diagnosed with Atypical HUS?

If you or someone you know has been diagnosed with aHUS, please contact PSI. At Patient Services, Inc. we aim to provide peace of mind to patients living with specific chronic illnesses by providing financial assistance to eligible persons.

Full Blog post found at **https://www.patientservicesinc.org/patient-blog/treating-ahus-this-disease-has-forever-changed-me**

My Mom Has Alzheimer's: 3 Things Every (First-Time) Caregiver Should Do

"The disease is fatal. There is no cure, so I feel like once the diagnosis is made, the medical professionals just put my mom into a holding pattern. She was put on level 1 hospice and it's like they just see her and pat her (and me on the shoulder) knowing she's going to die. Aging sucks, but this is not normal aging. This is a hopeless, terminal disease, so the system just gives up." Writes Jennifer, whose mom has Alzheimer's.

There are 5.7 million Americans who are living with Alzheimer's today. According to the Alzheimer's association, Alzheimer's disease is a degenerative brain disease and the most common cause of dementia. There is currently no cure for the disease which is the 6th leading cause of death in the U.S.

The current cost for treating Alzheimer's in America is $277 Billion with projections eclipsing $1 Trillion annually by the year 2050. And, as deaths related to heart disease have reduced by 11% over the past many years, deaths from Alzheimer's have increased upwards of 120%.

Watching a loved one endure such a horrific disease is not something to wish upon your worst enemy. But to also play role as caregiver is something only reserved for that of the selflessly courageous amongst us.

We recently interviewed Jennifer to learn more about her experience as both daughter of and caregiver for her mom with Alzheimer's.

What rare type of Alzheimer's does your mother have?

My mom has Alzheimer's from a traumatic brain injury. In her late 50s and early 60s, my mom had two bad falls that both resulted in concussions. Then in 2009, she suffered a subdural hematoma in her brain. Her Alzheimer's is similar to the type of Alzheimer's football players get.

Most people get Alzheimer's due to genetics, a disease like Parkinson's or just aging, but with my mom, it is clear her Alzheimer's came from the subdural hematoma in 2009. Her symptoms started right after that. There is no family history of Alzheimer's and my mom is the only person in her entire family who has ever had it … so far.

Though her Alzheimer's is roughly the same with the same symptoms, her path to it is very rare. (I read that only 1% of people with ALZ can track it directly to a brain injury. I can't find that stat anymore though, I looked.)

How does it affect the person differently than a more common form of the disease?

I can only write about my own experience with my mom. Most people experience a long time with mild impairments (things that seem normal like forgetting where you put your car keys or forgetting the name of someone you just met), but my mom seemed to go right into the moderate stage of Alzheimer's and skip the slow decline. Suddenly, she had a lot of symptoms and seemed very different than she was. So many people are diagnosed and have time to write things down, talk to loved ones, and prepare. But my mom was partially gone by the time we even knew what was going on.

Without a cure, how is this form of the disease treated?

It is treated the same way as traditional Alzheimer's and dementia is treated, with drugs that can slow the progression of symptoms, but not slow the damages of the disease. There are two medicines my mom took that did have some effect in slowing the progression of her symptoms. One was used to slow memory loss, confusion and other problems thinking, while the other was added as my mom's illness got more severe. My mom started taking these meds in 2016.

What does a normal week look like for treating this form of the disease?

A few years ago, my mom would see her doctor every few months. She was given control of self-administering Tylenol or other over the counter meds. She is cared for by Elder Place, a Providence organization, and they used to take her to their center every Friday for food and socializing. We went out a lot, so she didn't isolate herself. She did chair yoga. I felt like it was normal assisted-living stuff.

Now, my mom wears a tracking bracelet. She has an emergency necklace. She has a CNA who is responsible for being with or near to my mom while she is awake. Her case manager sees her often, she doesn't attend Elder

Place anymore because she doesn't respond to it (it makes her angry). Her medicines remain the same, but she is now on an anti-depressant and some medicine to help her sleep because she is so much worse at night.

Has treatment been effective?

Briefly effective, yes. But I know that the "treatment" was just masking the progression of the disease. There is no cure for Alzheimer's. It is 100% fatal. I did notice when my mom started taking the Alzheimer's meds that she hit a plateau and she didn't get a lot worse. We had a good couple of years where nothing seemed to change. Now the effectiveness of the medicines has worn off and my mom is in a steep decline.

When a diagnosis was made, what was the hardest part for you and your family?

The hardest part was understanding that the way my mom was acting was because of her disease and not because she was doing it on purpose to be hurtful. The other difficult part was deciding what living arrangements were best for her, specifically whether we should move her from Arizona to Oregon and where she should live.

How have you adjusted how you provide care from when you first started?

When my mom was first diagnosed, and we decided to move her up to Oregon, she was upset and angry and she no longer had a filter for what she said. I felt put upon when I started caregiving and I held back on loving my mom and accepting her. At the time, I got pretty upset and would leave a visit with her and tell myself if she was going to be mean to me then I didn't have to go visit her. I didn't have to call, and she deserved to be alone. It took a while for me to separate her from her disease, and eventually, I set aside time for regular visits with her.

Now my typical caregiving routine is very hands on. I talk to my mom every day to check in. I talk to her CNA almost every day to check in. I talk to her case manager once a week. I see my mom a few days a week. I still try and take her out a couple times a week, if she's up for it, but now I get there an hour or two early to visit and give her time to get ready. No matter what mood she is in or what she says, I am there. I console her if she was upset, I say "OK" a lot if I don't know what else to say and if she is in a good mood, it's a blessing.

What advice would you give families and first-time caregivers of those affected with this disease?

My first recommendation is to do a lot of research about Alzheimer's. Learn the symptoms, the stages of Alzheimer's progression, and get very involved with your loved one's doctors. Learn to be their advocate, because eventually they will not be able to advocate for themselves and they will rely on you.

Find an Alzheimer's support group and get to know other people who are caregivers. My mom doesn't live with me and for a while, I thought that I wasn't really a caregiver, so I shouldn't go to those meetings, but I am a caregiver and I do a lot. I carry a lot of weight and having someone to talk to who understands what I'm going through is so incredibly helpful.

Finally, find that wellspring of unconditional love inside yourself. You will need it in the most difficult times. Alzheimer's is stealing my mom from me one memory at a time, one day at a time, but I have also been blessed in a way I would never have thought possible. I've come to know who she really is deep inside. Her facade is gone, her anger had faded, her thoughts are jumbled, but her soul is still in there and I've built a relationship with her that I never would have had were it not for this disease. My mother raised us on her own. She worked three jobs, she had no social life to speak of, she gave up so much to make sure we had what we needed and wanted. Though it didn't feel like it at first, it is my blessing to be able to walk with her to the end of her life and take care of her.

Thank You Jennifer!

Patient Services, Inc., stands with Jennifer and the 5.7 Million battling Alzheimer's today. We would also like to thank Jennifer for sharing her story. We stand with you, your mom, and your entire family as you walk this journey together.

Do You Have A Caregiver Story?

If you or someone you know has a rare disease caregiver story, we'd love to hear from you. At PSI, patients, caregivers and advocates are the reason behind our drive, our fight and our passion.

Full Blog post found at: **https://www.patientservicesinc.org/patient-blog/my-mom-has-alzheimers-3-things-every-first-time-caregiver-should-do**

Social Media Update

At PSI, we want to keep our community in the loop by being transparent and timely.

That is why we work hard to maintain an active social presence on multiple platforms, including Facebook, Twitter, Instagram and PSI's LinkedIn. On these platforms, we post regular updates regarding PSI's operations and programs, resources to help our community and content we create for you. These platforms are where you will find the latest and most up-to-date information regarding PSI, as well as events and important call-to-actions, so we would greatly appreciate if you followed our channels. Our handle is **@PSI4Patients** on **Facebook, Twitter and Instagram**, and is simply **"Patient Services, Incorporated"** on **LinkedIn.** Please give us a follow, like or share our content!

We also have a podcast called **"Rare Perspectives,"** where we go beyond the diagnosis and dive into the stories of chronic and rare disease patients. Episodes are done in an interview style, and we talk with PSI patients, staff and members of other patient-focused organizations. Our primary goal is to educate our audience about chronic illness, as well as share the voices of those who live with the everyday reality of chronic disease. Each episode is released on a weekly basis on Spotify, Apple Podcasts and Soundcloud. Additionally, we recently switched to a video style of podcast, so episodes will also be released on YouTube in the near future! Give our podcast a follow on Spotify or Apple Podcasts, subscribe to us at **"Patient Services Incorporated" on YouTube** and leave us a podcast review so we can make better content for you in the future!

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