PATIENT SERVICES
INCORPORATED

ANNUAL REPORT 2018

LEADING PATIENTS TO POSITIVE OUTCOMES

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4/2018 to Present


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and Founder
Retired 4/2018


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Ways to Support PSI

Your Tax-Deductible Donation

For 29 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 2018, PSI received its tenth 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 also a Platinum charity with GuideStar. Thank you to the generous donors who gave to PSI in 2018 who are recognized in 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.

A New and Exciting Look!

In 2018, PSI launched a new and exciting look. Experience the big reveal that occurred in January 2018.

View our new brand launch video at: https://youtu.be/Pijp7jB12OA.

Ways to Give

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 our website at www.patientservicesinc.org.

Donate by mail: To donate by mail, simply send 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 programs, restoring hope and health to someone in need. Contact PSIDevelopment@uneedpsi.org for more details.

Thank You for Your Support!

On behalf of the PSI Board of Directors and Staff, the Program Development Department would like to express our sincere appreciation for your generous contributions made in 2018. Because of you, PSI provided $71.8 million in patient assistance in 2018. Thank you for restoring hope and health to our patients!

Program Development

Art Wood

Brittany Nicholson

Kara Witcoff

Karen Middlebrooks

Mandy Herbert

&CHALLENGE CHANGE

If there were a word to sum up the past year, it would be either *change* or *challenge*. Two thousand eighteen was certainly a year of significant change. The founder of the PSI model to help patients (which has been emulated by a number of other non-profits in the past fifteen years) retired, and I stepped into his shoes. These were big shoes to fill! Dr. Dana Kuhn, our former President and Founder, stepped down in April after serving the chronically ill for thirty years. Anyone who knows Dana knows that he is a person of great passion to help patients, as well as an avid advocate regarding those things that produce challenges to their access to treatment. Most of those who spend any time with Dana pick up on his passion as it is contagious. One of the things that has distinguished PSI from all other similar charities is our Government Relations and Advocacy branch. This grew out of Dana's ongoing advocacy over the years for patients. Many I talk to are surprised to hear that PSI is not simply a "copay foundation." They are impressed to not only hear that our financial support is much broader than simply copay, but also are most surprised to find out that we are active on Capitol Hill working to address some of the obstacles which have prevented many of our patients from getting their treatments. They are surprised to hear that we were the ones to fight for continued patient assistance for the rare disease communities when the Office of the Inspector General (OIG) said in 2014 that they would not allow any more patient assistance where there is only one manufacturer and one drug for patients. We worked with Congress and the OIG to find a way to allow all non-profits to continue to provide assistance to these rare disease populations. Many are surprised to hear that PSI is at the forefront fighting the insurance companies which are preventing charities such as PSI from paying for patients' assistance. Our bill in Congress is seeking to remedy this at a federal level as more insurance companies are finding ways to prevent patients from receiving third-party payer assistance.

The other word that comes to mind as I reflect back on 2018 is challenge. In addition to the challenges mentioned above, the regulatory environment has become so restrictive that it is increasingly difficult to have any meaningful interaction with those Pharma companies seeking to start a patient assistance program for new drugs coming to market. More and more of the patient access programs at these companies are being run by the compliance groups (either directly or indirectly). There is less conversation with those who are actually working with the patients and who have knowledge of the products. More and more decisions are being made by compliance staff who are quite separated from the day-to-day patient populations they seek to serve. Compliance is not a bad thing as long as it is balanced with an understanding of the needs of the patient populations and their struggles.

I greatly appreciate the donors who have continued to support the work of PSI in the midst of such a changing and challenging environment. I believe it takes great vision and concern for patients to continue to provide support in this environment of challenges. To those of you who display those characteristics, I salute you and say THANKS!

Art Wood
CEO

Government Relations

The Government Relations Department at Patient Services Incorporated concentrates on several specific areas including Advocacy on state and federal access issues, development of partnerships with state agencies and patient education. The major focus of the department in calendar year 2018 was the collection of cosponsors of H.R. 3976, the Access to Marketplace Insurance Act and moving the legislation through the legislative process.

Since 2014, the PSI Government Relations Department has led the efforts to overturn or at least modify a CMS Rule on Third-Party Premium Assistance. This work led to the introduction of federal legislation, H.R. 3976, the Access to Marketplace Insurance Act by Congressman Kevin Cramer (R-ND). By the end of the Congress, the bill had obtained 177 cosponsors. The assistance of the member organizations of the Marketplace Access Project (MAP) Coalition, which PSI has led, helped increase the numbers of cosponsors. The forces against the bill along with uneasy allies caused the bill to be held up. The Health Insurance industry campaigned hard against the bill holding it up from passing. PSI will work with our allies to reintroduce the legislation in the next Congress. On a state basis, PSI promoted the charitable assistance model. In California, legislators attempted to limit patient assistance organizations with legislation. PSI was able to modify the legislation to protect rare disease and chronically ill patients.

> The major focus of the department in calendar year 2018 was the collection of cosponsors of H.R. 3976, the Access to Marketplace Insurance Act and moving the legislation through the legislative process.

PSI will work to pursue partnerships with additional states in 2019. PSI currently has partnerships with agencies in Virginia, Kentucky and South Carolina. These programs target underinsured and uninsured patients with certain chronic conditions to transition into health insurance through premium assistance. As new and more expensive treatments come to the marketplace, PSI will continue to work with uninsured patients in other states.

PSI hosted our advocacy fly in April 2018 where we brought together patient advocates from across the country to advocate on the Access to Marketplace Insurance Act. PSI also continued to help state hemophilia organizations on their advocacy days in state capitols, including North Carolina, Kentucky, Virginia and Florida.

Our 2019 agenda for the Government Relations Department centers again around the Access to Marketplace Insurance Act. We look forward to working with patient groups and stakeholders to improve the lives of patients with rare and chronic conditions.

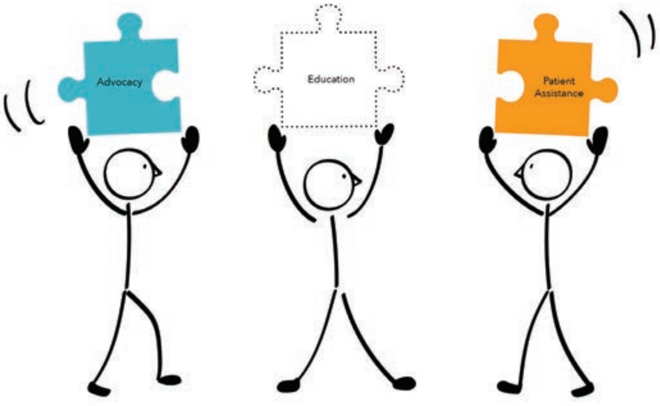
James Romano, MPA, MBA
Director of Government Relations

L-R: Lisa Wright; James Romano, PSI Director of Government Relations; Stephanie Fierman, Chris Templin; Brittany Nicholson, PSI Coordinator of Social Media

Operations and Program Reimbursement

Putting the Puzzle Together

Enhancing patients access to care through financial assistance has been the longstanding mission of PSI. With 29 years of experience in the patient assistance arena, we are confident that the mission has been successfully upheld. As the needs of our patients change, it is essential that we continue to evolve to meet the requirements. Financial assistance enables patients to receive necessary care and treatment to manage their condition. While this is a crucial piece of the complicated healthcare puzzle, there are often other pieces needed to see the whole picture and care for oneself. Over the last year, PSI has expanded to offer another piece to the healthcare puzzle – patient education. Navigating the healthcare system is complicated, and we understand the need to make educated and informed decisions when it comes to one's health. Through YouTube videos, webinars, and in-person educational sessions, PSI is equipping patients with the knowledge to make informed decisions regarding their health insurance and care. In 2018, educational topics included Medicare Open Enrollment, Marketplace Open Enrollment, General Health Insurance Terms, and Understanding Social Security and Disability through our PSI A.C.C.E.S.S. Program.



> *"Sometimes the hardest pieces of a puzzle to assemble, are the ones missing from the box."*
>
> ~Dixie Waters

Our Patient Service Representatives and Patient Access Specialists are committed to achieving the organizational mission. Each call and patient are treated with the utmost care and compassion to ensure that we are exceeding expectations. Approximately 274,000 minutes were spent talking to patients, family members, or providers and walking them through PSI assistance. While we strive to be as efficient as possible, we understand the need for a personalized experience, which will always be a core value.

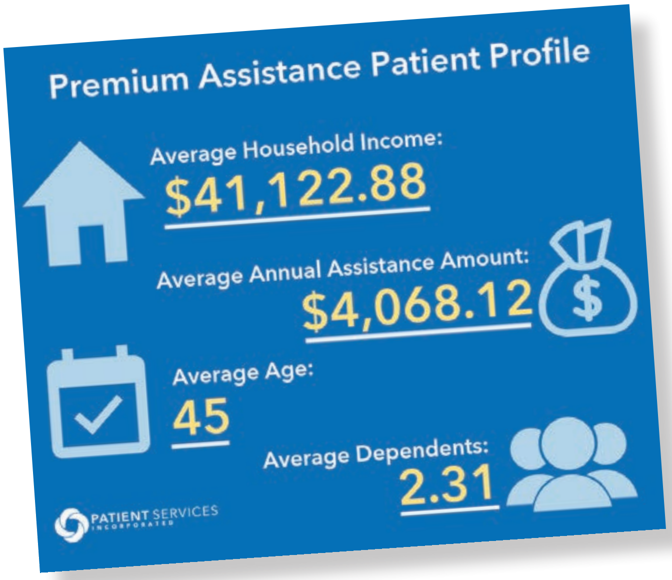
PSI has worked to ensure that patients are able to access their assistance when needed, putting their PSI assistance at their fingertips. Internally, this means that our staff is diligently working to improve processes. Our internal processes have become more automated and streamlined over the last year, allowing patients to self-manage their assistance. Subsequently, our call volume has decreased by 18%, although we continue to assist the same number of patients. In 2019, our efforts to implement additional efficiencies will continue. The PSI team is looking forward to partnering with our patients to continue putting the healthcare puzzle together.

Tiara Green, MSEd
Director of Operations
and Program Reimbursement

PSI Operations Department

Patient Profiles by Assistance

PSI provided $71.8 million in patient assistance in 2018. Through our programs, patients in need can access and afford treatment. Here’s a look at the types of assistance and amounts PSI provided in 2018.



Premium Assistance Patient Profile

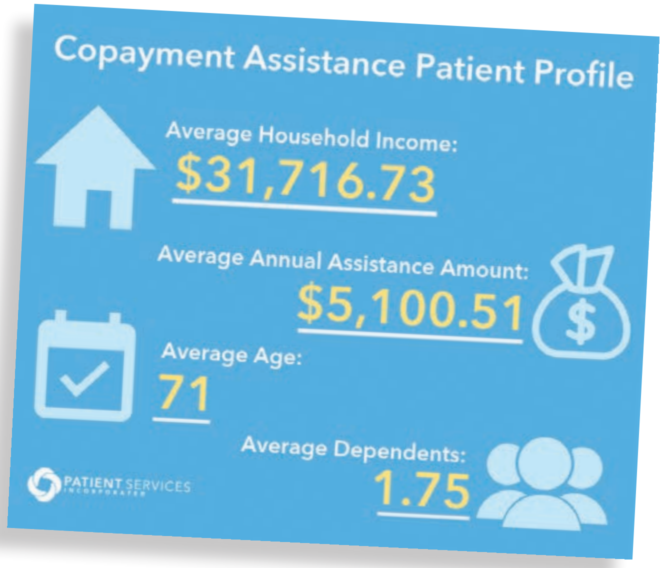
Average Household Income:
$41,122.88

Average Annual Assistance Amount:
$4,068.12

Average Age:
45

Average Dependents:
2.31

PATIENT SERVICES INCORPORATED



Copayment Assistance Patient Profile

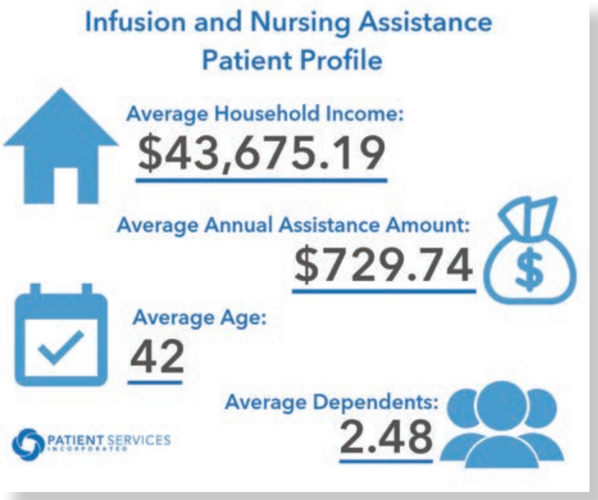
Average Household Income:
$31,716.73

Average Annual Assistance Amount:
$5,100.51

Average Age:
71

Average Dependents:
1.75

PATIENT SERVICES INCORPORATED



Infusion and Nursing Assistance Patient Profile

Average Household Income:
$43,675.19

Average Annual Assistance Amount:
$729.74

Average Age:
42

Average Dependents:
2.48

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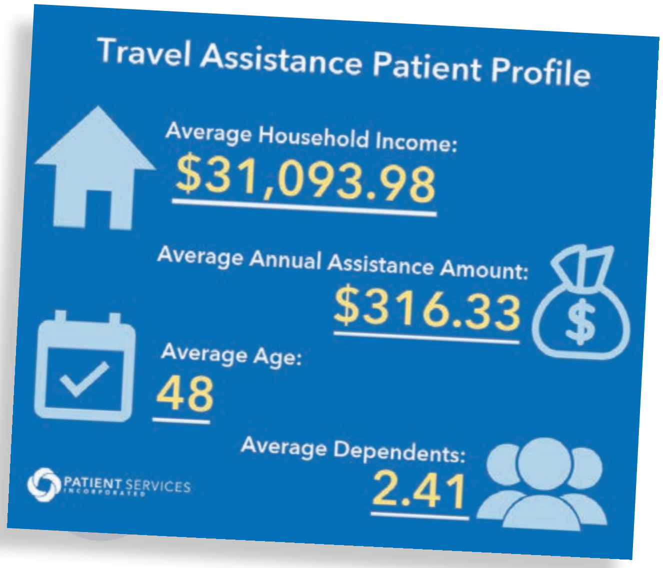


Travel Assistance Patient Profile

Average Household Income:
$31,093.98

Average Annual Assistance Amount:
$316.33

Average Age:
48

Average Dependents:
2.41

PATIENT SERVICES INCORPORATED

Improving the Patient Experience

With our focus always on the patient, we are continually improving our internal and external IT platforms for our patients and partners. Speed of service and ease of enrollment are the top priorities for our patients. With that in mind, we recently implemented an automated income verification service. This new tool allows PSI to verify a patient's income during the application process, thus reducing the required documentation needed and allowing patients to obtain service even faster. We have also implemented health insurance verification which streamlines the application process requiring less data entry from the applicant.

As we look to 2019, we plan to provide more flexibility with our assistance card options. In the past, a patient would have to carry multiple cards for each approved assistance type, i.e., travel, ancillary, etc. Going forward, patients will only need to carry one card, reducing confusion and frustration.

The organization continues to forge ahead for our patients, referral entities, and donors with innovation and an entrepreneurial spirit. We're looking to the future as we work to expand our communication efforts to our patients by implementing new communication tools via our portals as well as offering text messaging options. Our patients will also be receiving surveys to help us better understand their expectations and learn what other services and offerings they would like to see. A mobile application is currently underway that will allow patients to manage their assistance, view their application status, and apply for assistance all from their smart device. As always, all our offerings are and will continue to be HIPAA compliant to ensure patient data is secure and held private.

Our future technology at PSI only continues to grow stronger and become more stable. We're here for you, our patients and end users. Always evolving, we are committed to remaining at the forefront of current technology trends and those of the future, while keeping in mind the needs of our patients.

Stacey Pugh
IT Project Manager

PSI IT Department

> Our future technology at PSI only continues to grow stronger and become more stable. We're here for you, our patients and end users.

Stacey Pugh
IT Project Manager

A.C.C.E.S.S.® Program

PSI A.C.C.E.S.S. closed 2018 with 57 active disability cases. Our attorneys appeared at 41 hearings across the country during the past year and we resolved a total of 57 claims. A total of 78% 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	**58%**
Alpha 1	**25%**
Immune Deficiency	**16%**
Pulmonary Hypertension	**1%**

In the close to ten years since our program joined PSI in 2009, we have represented 872 clients and appeared at 479 hearings.

> There is presently great uncertainty as to how high-risk populations will qualify for or afford healthcare. In this changing environment, our goal is to continue exploring expansion of services to our core communities …

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 access to healthcare coverage.

Since launching in May of 2013, the PSI A.C.C.E.S.S. Legal Support Hotline has fielded more than 700 calls. 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.

We expect that it will become ever more challenging to qualify our clients for disability benefits, as the national trend towards denying more and more applications continues. Wait times for resolving these claims are also likely to increase.

Bill Leach
A.C.C.E.S.S. Supervisor and Attorney

PSI A.C.C.E.S.S. Team

L-R: Terry Staletovich, Attorney; William Leach, A.C.C.E.S.S. Supervisor/Attorney; Carolyn Burke, Receptionist; Kathy Crowe, Senior Disability Claims Specialist

Finance Report

Patient Services, Inc. continued to maintain a solid financial position in 2018. The Balance Sheet is strong, with adequate reserves to meet our program obligations. Revenues of $72 million were close to expectations, albeit lower than near record 2017 levels, due in large part to pledge timing impacts. We remain grateful for the continued generous support from our donors, both long-term supporters and those new to advancing PSI's mission.

In 2018, PSI provided financial assistance to 16,341 patients for a total of $71.8 million in direct program services, providing an average of $4,395 per patient assisted. Over 92% of the organization's total functional expenses were spent on program services. Cost containment efforts contributed to a 20% reduction in total administrative expenses.

Our Finance Department's experienced and dedicated staff takes pride in operating efficiently and effectively. From collecting and recording donations to disbursing funds to patients and vendors, we process thousands of transactions annually in support of the organization's eighty disease programs.

Our financial statements and programs are audited annually by an independent accounting firm. Once again, PSI received a favorable unqualified audit opinion in 2018. A copy of our 2018 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 2018.

Daniel Wise
Director of Finance

Summary Statement of Financial Position
December 31, 2018 and 2017

ASSETS	**2018**	**2017**
Current Assets	$100,911,034	$113,068,905
Property and Equipment	2,115,831	2,220,755
Other Assets	6,928,276	7,197,956
Total Assets	$109,955,141	$122,487,616
LIABILITIES AND NET ASSETS		
Current Liabilities	$828,111	$1,102,362
Net Assets without donor restrictions	16,647,070	17,537,574
Net Assets with donor restrictions	92,479,960	103,847,680
Total Liabilities and Net Assets	**$109,955,141**	**$122,487,616**

Statement of Activities (2018 and 2017)

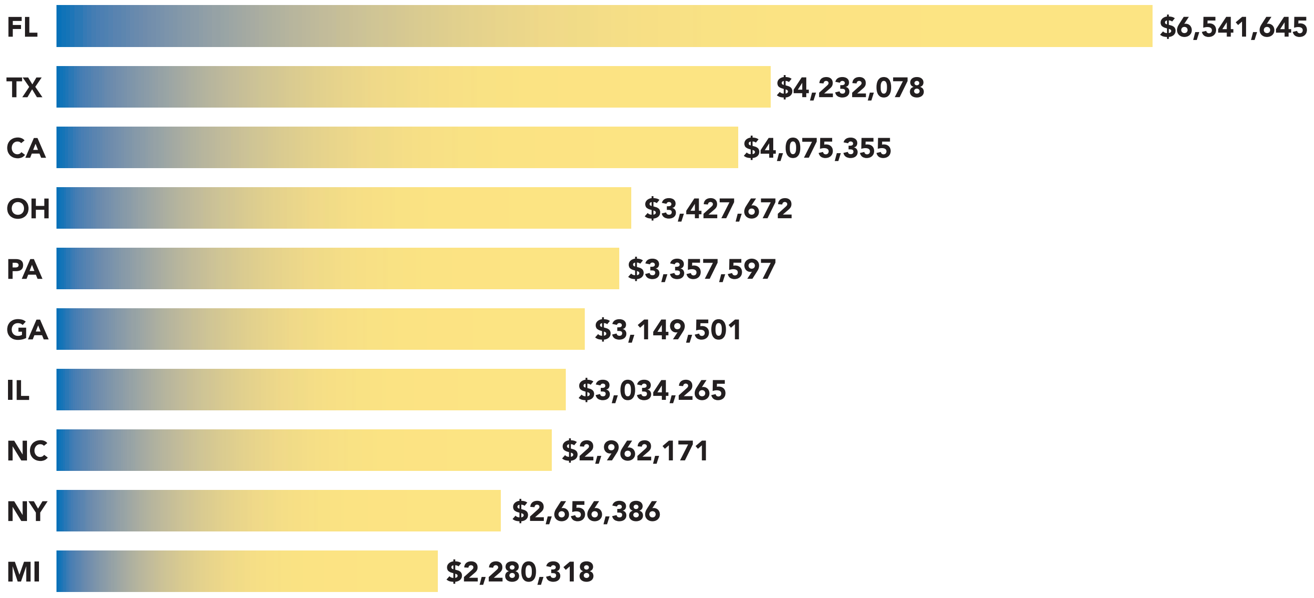
	Without Restrictions	With Restrictions	Total 2018	Total 2017
REVENUES AND OTHER SUPPORT				
Contributions	$7,970,691	$62,374,450	$70,345,141	$116,167,682
Fees for contracted services	140,990	1,341,419	1,482,409	2,204,119
Interest income	236,733	–	236,733	131,059
Miscellaneous income	57,442	–	57,442	75,134
Gain (Loss) on Investments	(392,180)	–	(392,180)	553,199
Net assets released from restrictions	71,828,591	(71,828,591)	–	–
Total revenues and other support	**79,842,267**	**(8,112,722)**	**71,729,545**	**119,131,193**
EXPENSES AND LOSSES				
Program services	74,292,257	-	74,292,257	95,135,999
Fundraising	903,932	-	903,932	942,116
Management and general	5,242,575	-	5,242,575	7,289,248
Total functional expenses	80,438,764	-	80,438,764	103,367,363
Uncollectible pledge expense	294,006	3,255,000	3,549,006	25,000
Total expenses and losses	**80,732,770**	**3,255,000**	**83,987,770**	**103,392,363**
Change in net assets	**(890,503)**	**(11,367,722)**	**(12,258,225)**	**15,738,830**
NET ASSETS				
Beginning of year	17,537,573	103,847,682	121,385,255	105,646,425
Ending	**$16,647,070**	**$92,479,960**	**$109,127,030**	**$121,385,255**

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 visiting our website, www.patientservicesinc.org.

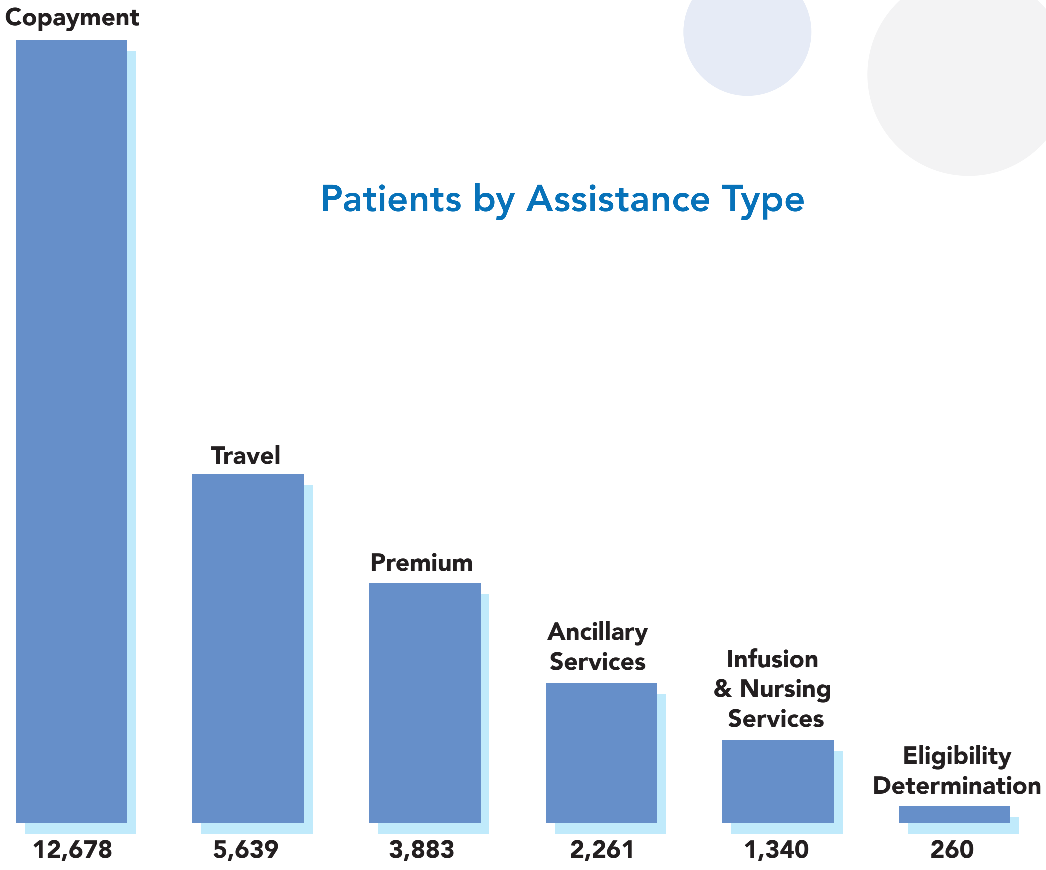
PSI Accounting
& QA/QC Team

Financials *(Year ended December 31, 2018)*

Financial Assistance by Top 10 States

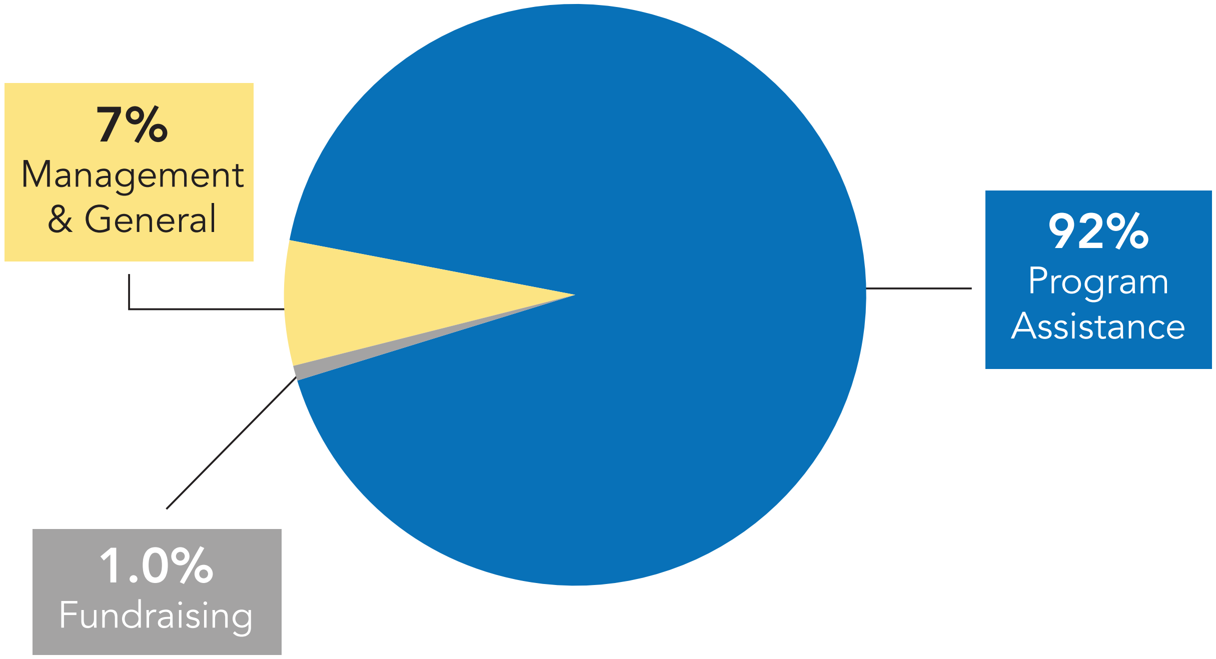


Patients by Assistance Type



Note: Patients may be enrolled in more than one assistance type.

Functional Expense



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

Patient Blog – *New in 2018*

In 2018, PSI launched a patient blog allowing those we assist to share their stories about living with a chronic illness. A few of these inspiring posts are shared within the next few pages. Through their words we regain hope and encouragement!

To read more blog posts visit our website: **https://www.patientservicesinc.org/category/patient-blog.**

To be featured on the blog please contact **PSIDevelopment@uneedpsi.org.** To submit a short testimony, visit **https://submissions.patientservicesinc.org/forms/yourstory.**

We look forward to hearing from you, thank you for being part of the PSI family!

Heartbreak to Hope: Where Two Families Found Relief

In 2015, Sandy's husband, then 45, suffered two strokes. The result left him both disabled and unable to work. One of the many effects from these two strokes was a condition known as Pseudobulbar Affect (PBA).

Pseudobulbar Affect is a condition, according to pbainfo.org, that causes uncontrollable crying and/or laughing that happens suddenly and frequently. It can happen in people with a brain injury or certain neurological conditions. A person having a PBA crying spell may cry when they don't feel sad or when they only feel a little bit sad. Someone having a PBA laughing spell may laugh when they don't feel amused or when they only feel a little bit amused.

For many who suffer daily from Pseudobulbar Affect, relief has come with the advancement of medications that provide a renewed sense of normalcy to their lives. Yet sadly, as we hear time and again, it's the cost of treatment and these very medications, that too often, seek to stand between the patient, and getting their lives back, and for many even still, actually saving their life.

For Sandy and her family, it has left her being the only one able to work. Though they do have health insurance, it does not cover the entire cost of the medication her husband so desperately needs. For them, there is but one medication that works, and the cost is alarming. This left them at the crossroads of facing a far too common reality.

Not able to afford treatment, a conclusion was made that for Sandy's husband, he would have to stop taking the medication. In her words, "He cannot live a half normal life without it." The anxiety and depression that he faced every single day was beyond debilitating.

But something happened. Someone told her about Patient Services, Inc.

"PSI is 100% responsible for saving my husband's life. The financial help they have given us for his medicine is nothing short of a miracle for us. I thank God for these men and women who are so selfless and this organization for their help. Without them I would have to also hire someone to sit with my husband while I work if he didn't have this medication. Thank you PSI. You will never know the impact you are making in our lives as well as others across the country. We are forever grateful.   May God bless you all." Sandy tells us in an email she had recently sent to us.

Overcoming The Doughnut Hole: Jerry's Story

When Melissa's husband Jerry was diagnosed with a brain tumor in October of 2008, their son was just 11 months old. Fortunately, Jerry did not have to undergo radiation or chemo until 5 years later when the tumor first showed signs of growth. That was 2013.

Since then, Jerry has battled severe anxiety and depression and has tried multiple medication regimens to aid in these treatments. Most recently, in 2017, his neurologist offered to try a new medication that was being used to treat anxiety and would possibly offer a bit of normalcy back to our routines and would allow him a bit more freedom that he so desperately wants.

Melissa tells us, "They were right. The medication has been a breath of fresh air. The only problem, it is extremely expensive. Medicare pays for most of it, but it causes him to reach the "doughnut hole" so quickly that we end up owing more than $400 each month for the medication that he so desperately needs. This $400 doesn't include the other 11 medications that he takes on a daily basis."

But again, like Sandy and her husband, Melissa found out about PSI.

"Without PSI, we never would have been able to keep up his regimen of the daily medication (twice a day) that allows him the freedoms to live outside of crushing anxiety. My son wouldn't be able to enjoy his father in a way that he should be able to, like other children are able to spend quality time with their fathers. My husband's original prognosis was 5 to 10 years and this year, marks 10 years. We have never focused on the prognosis, but it has always been in the back of our minds (how could it not?) and we pray each day for another good day and Jerry's medication with the help of PSI gives us those good days."

From heartbreak to hope, we're honored to have played a part in helping these two families find relief from the overwhelming costs of their medication.

Two Words

For the employees at PSI, these two stories represent many more of why we wake up each morning and cannot wait to get to work. We are honored to have an opportunity to come alongside those battling rare disease and chronic illnesses in a way that might bring them perhaps a sliver of hope. For it is in each of their stories, that we find strength, courage, and inspiration. And it is here, where we find in ourselves, a new hope for our own lives.

Simply put, for all those we get to work for and fight for every single day, we have two words for you – *you matter.*

If you or someone you know has been recently diagnosed with a rare disease or chronic illness, please visit our website and learn about the work of PSI. We'd also be honored to share your story.

Everybody has a story, especially a story if you have a child or a family member with a chronic illness. Your story matters and can change people's lives. We believe that it can change people's minds. We need your help to continue to share your stories, and to continue to express your first amendment right. Will you join us? Take action today by clicking **https://www.patientservicesinc.org/advocacy/health-care-charities-save-lives-and-taxpayer-dollars.**

Together, we can make a difference.

Lisa's Story: What Kept This Fabry Patient Going?

At the age of 49, Lisa's lifelong mystery had finally been solved. It was just 10 months earlier that her twin sister was diagnosed with the very same rare disease. And although the discovery has brought closure to so many unanswered questions, it has also led to a thousand more.

"By the time I was diagnosed with Fabry, the symptoms were bad. It affected my heart and nerves. I couldn't imagine how I was going to care for my children and myself. I didn't want them to experience the constant pain and discomfort I had felt all my life." Lisa tells us as she recalls when she was first diagnosed.

Fabry is a rare genetic disorder caused by a defective gene (the GLA gene) in the body. In most cases, the defect in the gene causes a deficient quantity of the enzyme alpha-galactosidase A. This results in a buildup of a particular type of fat, called globotriaosylceramide, in the body's cells.

There is no cure for Fabry and treatment, well, that led to another question. At roughly $200,000 a month for infusions, how could anybody begin to afford it? We asked Lisa about her treatment, what it does, and how she faced the enormity of it all.

"I get an enzyme replacement treatment at home now thanks to PSI. The purpose of ERT is to replace the enzyme that I cannot make on my own. The enzyme is infused into the vein by IV every other week and is taken up by the cells. Once it enters the cells, the enzyme can remove the stored GL3 and improve cellular function. This should stop GL3 from building up and hopefully stop or slow the progression of the disease symptoms and health problems." Lisa explains.

After diagnosis, but before treatment was a test of faith for Lisa and her family. When they had found out about the cost of the infusions, they wondered what they were going to do and why it was so expensive. Lisa tells us what happened next, "After my diagnosis and once I agreed to treatment, I was assigned to a case manager who told me about PSI and the assistance I could get since I was not working. Before I learned about PSI, I thought I would just die from this disease. I could not afford the $200,000 a month for infusions."

Taking a moment to look back at life through the lens of unanswered questions, Lisa reflects on what it was like growing up while not knowing what was going on with her.

"It was lonely, confusing, isolated, frustrating and restricted. I did not understand why I felt so bad and nobody knew what was wrong. Why gym activities, playing outside, skating or simply going for a walk on a nice summer day were so difficult for me? I missed out on a lot of things during my childhood due to the pain and fainting."

And yet, it wouldn't be until the age of 49 when Lisa would get her answer. What kept her going? One could only imagine the amount of times anyone suffering such plight would want to give up and throw in the towel. We asked Lisa what kept her going.

"Having a rare disease is physically, emotionally and mentally draining. Many times before the diagnoses I felt like what's the use. I needed the pain to stop. No one knew what was wrong with me so it made me feel like I was crazy. I kept going because I had trust that God would not put more on me than I can bear. It wasn't fair for me to give up on my family so I had to fight."

Stop for a moment.

Re-read that quote for perspective.

[Insert your current situation here.]

Continue reading.

In April of 2015, Lisa was finally diagnosed with Fabry. We asked Lisa what that day was like when she received the news.

"My twin sister was diagnosed 10 months before and told me I should get tested since I was having issues with my blood pressure and heart for years. I was reluctant at first because our symptoms were different, and I did not clearly understand at the time that it was a genetic disease. I had mixed emotions that day. I was relieved to have an answer, the mystery was finally solved after 49 years but I was also sad and angry. The test was done by the geneticist. My PCP then called me one day and asked me to come in immediately, when I arrived, she gave me the results even though she didn't know about the disease."

With Lisa's twin sister Linda having been previously diagnosed with Fabry, the effect this rare disease has had on their entire family both before and after diagnosis has been significant. When Linda was diagnosed she had learned that she was not alone. Many in their family had too, been diagnosed with Fabry. Matter of fact, there were already nine cousins living with the disease.

For Lisa, her Fabry diagnosis has helped her to be more understanding as to what each of her siblings were experiencing. Fabry had effected each of them differently. Yet, they all feared how the late diagnosis would effect them.

Lisa, now armed with tools, resources, and knowledge, along with treatment to help face her Fabry diagnosis, loves to share with others that which she has learned. We asked Lisa what she would say to someone that had been recently diagnosed with Fabry, "That it is a scary invisible disease, but they are not invisible or alone. There is hope, help, support, treatment, and others who understand. Educate yourself about the disease so you can be your own advocate. Take care of yourself physically and emotionally and advise family members to get tested and get treatment early."

Lisa and her twin sister Linda, with PSI's James Romano

Lisa has so much wisdom to share with others. And we have so much we can learn from Lisa about that which is truly important in life. In closing, Lisa shared three pieces of advice with us about what's really important in life.

Health, take care of yourself and your health.

Don't give up. Even if discouraged keep pursuing one step at a time.

Be supportive. Everybody needs support, there are many things in life that are hard to battle alone.

At PSI, we are honored to be walking the road with both Lisa and her twin sister Linda and so many others like them. We are better because of them in our lives. And the world, is that much brighter, too.

Thank you to Lisa for sharing your story with us. If you want to know what you can do to help support the Fabry community, Lisa offered this advice:

"Raise awareness and donate. This is a genetic disease that affects families. In my case we all have Fabry and no one in my family is working. Myself, my mother and all my siblings all have the disease. We all were diagnosed late in life so went decades without treatment. All of us are now on disability so it becomes challenging trying to help each other when nobody is able to work."

Looking Back on 2018

$71.8 million

paid out in direct patient assistance

In 2018, PSI assisted over

28,000

active patients

Assisted with over

185,000

claims

Educating patients through

Videos

Webinars

In-Person Sessions

Social Media Following in 2018

99% increase	31% increase
45% increase	34% increase

21%

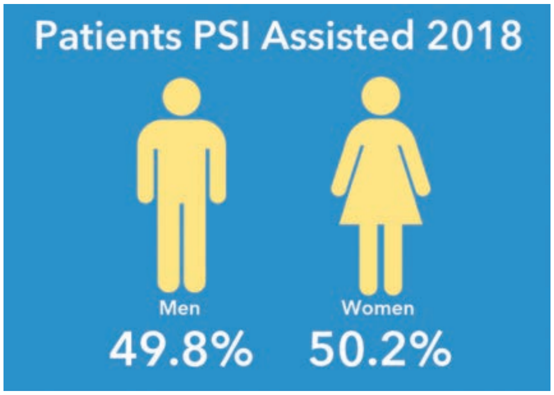
Could you afford to dedicate this percentage of your income to life-saving medications?

This is the percentage of Americans living with a chronic illness.

60%

RAND study

Patients PSI Assisted 2018



Men	Women
49.8%	50.2%

Looking Back on 2018

Received over

15,000

new applications for assistance

Facebook

Top-performing social media platform with over 26,000 engagements. This means our audience is sharing, liking and commenting on the information we post!

Over

92%

of total functional expenses were spent on patients.

Assisted with over

150

diagnoses

Reduced call volume by

18%

while assisting the same number of patients in 2018 due to internal efficiencies.

8 On average, a patient receives financial support from PSI for **months**

TOTALING TO

$4,896.00

Over **274** thousand minutes spent talking to patients, family members or providers in 2018.

PATIENT SERVICES INCORPORATED

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