

2017 Impact Report



to provide critically or chronically ill individuals with access to advanced therapies through

Mark P. McGreevy, President and CEO – The Assistance Fund

“WE KNOW HEALTH IS NOT JUST MEASURED BY A LAB TEST RESULT. IT’S A FUNCTION OF A PERSON’S OVERALL WELL-BEING, AND WE KNOW THE FINANCIAL AND EMOTIONAL SUPPORT WE PROVIDE IS A BIG PART OF THAT FOR MANY PATIENTS.”

a continuum of services and programs, including education and financial aid.



Mark P. McGreevy, President and CEO
The Assistance Fund



president's letter

Dear Friends,

It is hard to believe another year has passed. 2017 was full of growth and innovation, and we made great strides in furthering our mission to ensure all patients have access to the medications they need regardless of their ability to pay. Throughout this report, we share some of the accomplishments we are most proud of from the past year.

A major highlight is the significant growth in donations in 2017, which surpassed our growth in all prior years. We experienced a 38 percent increase in donations over 2016, totaling \$164 million for the year. These funds enabled us to assist more than 43,000 patients during the course of the year and open four new disease programs: Gaucher Disease, Hunter Syndrome, MPS VII – Sly Syndrome and Myasthenia Gravis, bringing our total number of programs to 40. We are thrilled by the addition of these programs and the impact they allow us to make on the lives of patients.

While we are grateful to our donors for supporting our mission, we are equally grateful to have an outstanding staff and board of advisors who work daily to make a positive difference in patients' lives. From our Medical Advisory Board, to our patient advocates, to our many other staff members, each member of the TAF family plays a vital role in giving patients a voice and ensuring they are able to get access to the medications they need by helping them navigate the often-complex financial landscape associated with their medical care.


Only a few organizations get to see first-hand the impact they make on people's lives. We are fortunate enough to see our impact each and every day. In 2017, TAF patient advocates answered approximately 16,000 calls per month. As the months turn into years, the volume of our impact only continues to grow.

This year's Impact Report is organized around the journey people take through the healthcare system, from diagnosis to treatment. We are pleased to share with you how The Assistance Fund put our resources to work in 2017 to help patients along the way.

Kind regards,

A handwritten signature in black ink, appearing to read 'Mark McGreevy', with a long horizontal flourish extending to the right.

Mark P. McGreevy
President and CEO
The Assistance Fund

A close-up photograph of two women smiling warmly at each other. The woman on the right has dark, wavy hair and is wearing a red top. The woman on the left has curly hair and is wearing a light-colored top. They are outdoors, with a blurred background of green foliage and sunlight filtering through the leaves, creating a bokeh effect.

**“I’VE BEEN DIAGNOSED WITH STAGE IV
METASTATIC MELANOMA THREE TIMES.
THE FIRST TIME, MY COWORKERS HAD NO
IDEA. BECAUSE I DON’T LOOK SICK. THEY
CAN’T SEE INSIDE.”**

Elaine, Melanoma Copay Assistance Program



The Starting Point: Diagnosis

Coming to terms with a diagnosis isn't easy, and we understand the difficulties patients face when first learning of a diagnosis. It can be intimidating and scary, and raise a host of questions. Many of the patients that The Assistance Fund helps are living with chronic or rare medical conditions. The long-term implications of these types of conditions can be significant.

It's important for patients to know that they are not alone. By 2020, the number of Americans living with chronic diseases is expected to reach 157 million and 81 million will have multiple conditions.ⁱ This means that more and

more people are facing the realities and difficulties of managing a chronic disease. In addition, one in every 10 Americans is living with a so-called rare disease, meaning a condition that affects fewer than 200,000 people.ⁱⁱ

At The Assistance Fund we recognize that whether a condition is rare or chronic, new or lifelong, it means change, and we are here to help.

40 PROGRAMS

The Assistance Fund has 40 programs supporting a variety of diseases and conditions



33,000
ONLINE CHAT

SESSIONS WITH PATIENTS & PROVIDERS IN 2017



SIXTEEN
PATIENT ADVOCATES
TO SERVE PATIENTS & PROVIDERS



CALLS HANDLED IN 2017:

195,000



support



43,000
PATIENTS
ASSISTED IN 2017



4 NEW
PROGRAMS

GAUCHER DISEASE, HUNTER SYNDROME, MPS VII
– SLY SYNDROME AND MYASTHENIA GRAVIS



96%
OF EXPENDITURES
HAS BEEN DIRECTLY
ASSOCIATED WITH
PATIENT ASSISTANCE
SINCE INCEPTION

\$164 MILLION

\$164 million raised in 2017, a 38% increase in donations over 2016

Medications

Every year, new medications are available to help people treat and/or manage their health. Finding the right medication can be a process. What works for one patient may not work for another and finding what does work may be time-consuming and frustrating. Fortunately, new medications are transforming the treatment of many diseases. In 2016, for example, the FDA approved the first treatment for Duchenne muscular dystrophy. In 2017, the FDA approved the first biologic treatment for atopic dermatitis.

In total in 2017, the FDA approved 46 novel drugs, of which 14 were the first drugs in their class, and 18 were for rare or “orphan diseases.”ⁱⁱⁱ Unfortunately, developing these treatments requires enormous investment by


the pharmaceutical and biotech industries, and they sometimes come with high price tags, particularly when they are designed to treat relatively small patient populations.

At The Assistance Fund, we monitor pharmaceutical industry innovation closely, working with our medical advisory board to ensure that TAF is developing programs that cover disease states with FDA-approved therapies. We reach out to companies that are bringing new, innovative therapies to market to get funds to cover more patients. Our goal is to ensure that these potentially life-changing medications can make it to those who need them.

A young woman with brown hair tied back, wearing blue scrubs, is smiling and leaning over an elderly woman. The elderly woman has short, wavy grey hair and is wearing a light blue button-down shirt over a white top. She is seated in a wheelchair, and the young woman is holding her hand. The background is a bright, out-of-focus indoor setting.

**“MY MEDICATION COSTS \$60,000
A MONTH AND IT WORKS SO WELL.
I WAS TERRIFIED, MY FAMILY AND
I TALKED ALL THE TIME ABOUT HOW WE
WOULD BE ABLE TO PAY THE COPAY.”**

Robin, Myasthenia Gravis Financial Assistance Program



**“IT WAS SCARY, BUT I DIDN’T HAVE
A CHOICE. WHEN TAF CALLED ME,
IT WAS A MIRACLE. FROM THE BOTTOM
OF MY HEART, I’M CERTAINLY GLAD YOU
ALL ARE THERE.”**

Michele, Multiple Sclerosis Copay Assistance Program



Insurance

Insurance coverage is critical to health. In the past two decades, the benefit design of commercial and government insurance coverage has become increasingly complex, particularly when it comes to drug coverage. Many plans have separate deductibles for medical treatments (doctor and hospital visits) and medications. Some plans have multiple tiers of copayments for medications or coinsurance reimbursement structures. Some innovative medications may not be covered, while some biologics (known as “specialty drugs”) may be covered as medical treatments.

According to a May 2018 report by health data firm IQVIA, patients have seen an increased cost exposure over time due to changes in benefit design.^{iv} Between 2013 and 2017, there has been an increase in reliance on deductibles and coinsurance. The effect of this is that more patients are now exposed to high drug prices, whereas when benefit designs favored copays, the impact of high prices was more limited.

At The Assistance Fund, we aim to alleviate the out-of-pocket burden for qualified patients who are diagnosed with a condition one of our programs covers. Whether you are prescribed a generic medication or a newly-approved treatment, TAF covers the costs so that patients can focus on what matters — their health. We are dedicated to ensuring patients have access to the medications they need and over the past nine years, we’ve had great success in doing just that.

28 MILLION

THE NUMBER OF AMERICANS WITH NO INSURANCE

THE PRIMARY REASON: **BECAUSE INSURANCE COSTS ARE TOO HIGH¹**



7 OUT OF 10 WHO REPORT PROBLEMS PAYING MEDICAL BILLS REPORT CUTTING BACK SPENDING ON FOOD, CLOTHING OR BASIC HOUSEHOLD ITEMS³



3 out of 10 Americans report problems paying medical bills²



#1

REASON TO BE CONTACTED BY A COLLECTIONS AGENCY IS FOR PAST-DUE BILLS OR PAYMENTS FOR MEDICAL DEBT⁴



\$5,714

The average annual cost for a family's employee portion of their health insurance⁵



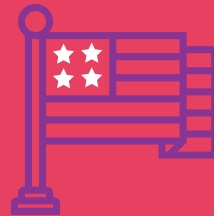
Supporting The Journey

The creation of The Assistance Fund was inspired by an all-too-common story of a patient at risk of not being able to afford the medication she desperately needed. A 2010 study showed that consumers who faced a copay of \$50 were four times as likely to abandon their treatment at the pharmacy counter than consumers asked to pay a \$10 copay.⁹ Imagine what that figure would be for out-of-pocket costs in the thousands of dollars. This is why what we do at The Assistance Fund is so critical.

Our 16 compassionate and experienced patient advocates man our phone lines from nine to six, five days a week, year round, and handled more than 195,000 phone calls in 2017. Patients and providers can chat with us online too: we engaged in almost 33,000 chat sessions in 2017.

We are also always looking for ways to improve our technology to make working with us as seamless as possible. In 2017, we launched a document upload system on our website and a new telephony system, which has an automated self-help menu for patients and providers. Patients can now call 24/7 to check their enrollment, reenrollment and reimbursement status. Providers can check patient enrollment status and funds availability.

Another important part of making the patient journey as stress free as possible is our commitment to maintaining our patient's coverage. Once a patient is enrolled in one of our programs, their coverage lasts the entire calendar year. There is no cap on the amount of assistance an enrolled patient can receive during the year.



50 STATES

PATIENTS IN 50 STATES & PUERTO RICO RECEIVE ASSISTANCE FROM THE ASSISTANCE FUND

195,000 CALLS HANDLED

50,000+ claims per quarter processed on average

13,000+ DOCUMENTS UPLOADED PER QUARTER ON AVERAGE



4,300+

CALLS TO THE SELF-HELP PHONE SYSTEM OUTSIDE OF OFFICE HOURS



<\$40,000

average household income of enrolled patients



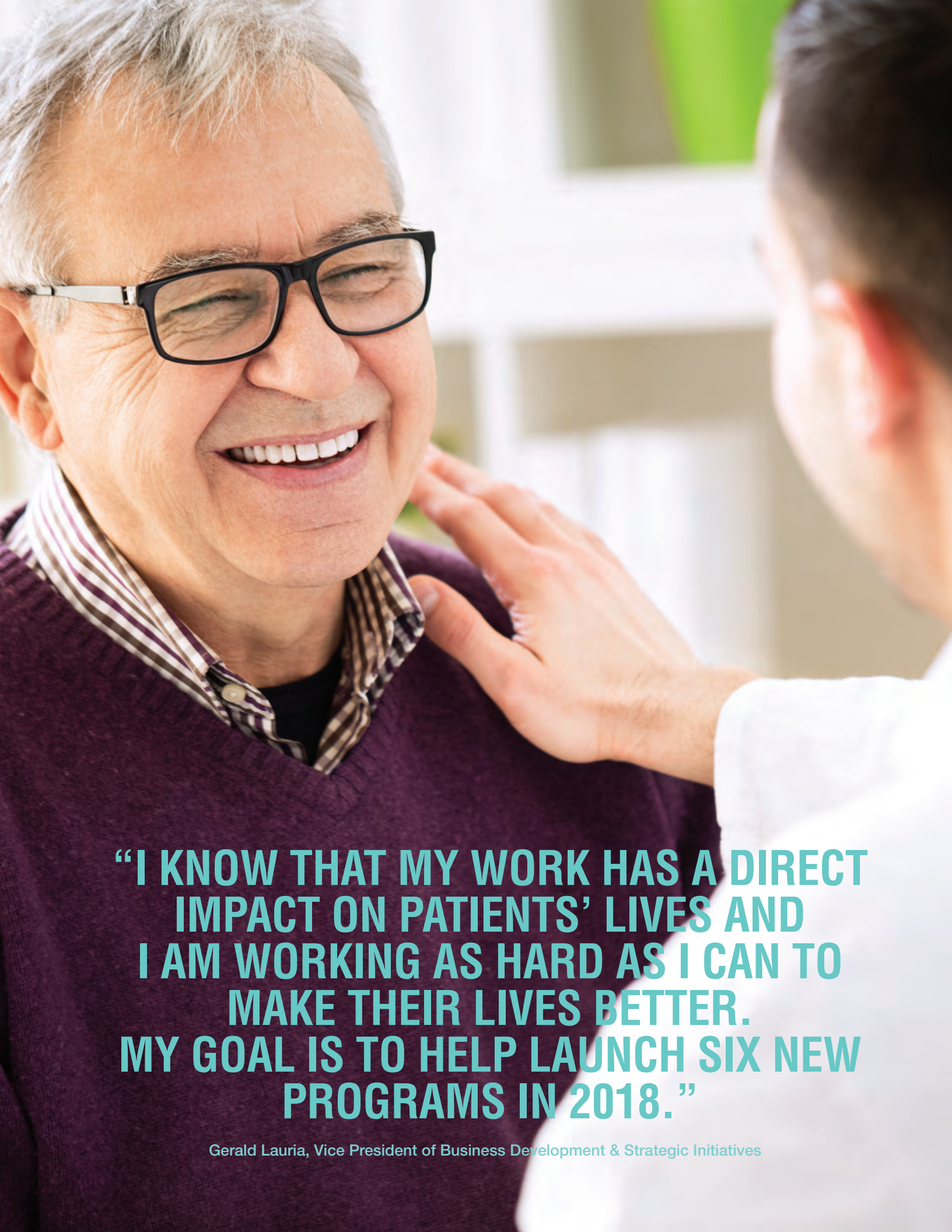
**“IN CAME TAF AND
THEY HAVE MADE
THIS AS EASY AS IT
COULD POSSIBLY
BE AND FOR THAT
I AM ETERNALLY
GRATEFUL.”**

Anonymous, Primary Biliary
Cholangitis (Cirrhosis)
Financial Assistance Program



**“I REALLY ENJOY
REACHING OUT TO
OUR NEWLY ENROLLED
PATIENTS... THEY
EXPRESS A LOT OF
GRATITUDE.”**

Jodine, TAF Patient Advocate



**“I KNOW THAT MY WORK HAS A DIRECT
IMPACT ON PATIENTS’ LIVES AND
I AM WORKING AS HARD AS I CAN TO
MAKE THEIR LIVES BETTER.
MY GOAL IS TO HELP LAUNCH SIX NEW
PROGRAMS IN 2018.”**

Gerald Lauria, Vice President of Business Development & Strategic Initiatives



Expanding Our Impact

2017 was a year of significant growth for The Assistance Fund. We raised \$164 million, a 38 percent increase over 2016. These contributions supported 40 disease programs, which aided more than 43,000 people with their copays, coinsurance, deductibles and, in some cases, travel and incidental medical expenses.

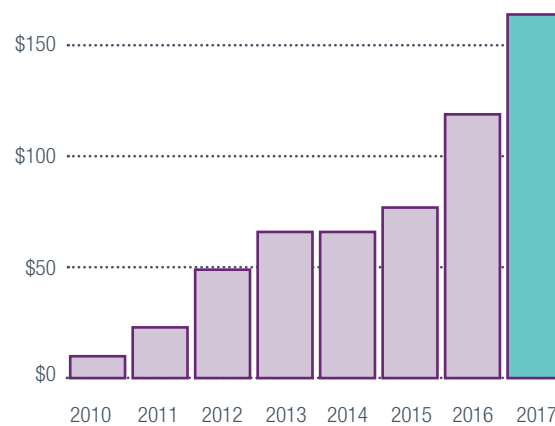
We were able to launch four new programs: Gaucher Disease, Hunter Syndrome, MPS VII – Sly Syndrome and Myasthenia Gravis thanks to these donations. Our growth aspirations for 2018 are even greater, which is why we've been active behind the scenes spreading the word about The Assistance Fund and advocating on behalf of our patients.

This past year we've also been on the road attending conferences, summits and meetings to connect with key stakeholders, from patients to specialty pharmacies to advocacy groups to donors. Building these connections will help facilitate the creation of new programs and enable us to reach a larger number of patients who may be struggling to afford the cost of their medications.

In 2017 we assisted more than 43,000 patients, almost twice as many as we assisted in 2016, and we are proud to say that over 95% of expenditures was directly associated with patient assistance.

DONATIONS

(dollars in millions)



\$164 MILLION

IN 2017, DONATIONS TO TAF INCREASED BY 38 PERCENT, TO \$164 MILLION

FUND SPOTLIGHT

YEAR FUND LAUNCHED:

2016

PATIENTS ASSISTED IN 2017:

228

Individuals with Duchenne muscular dystrophy begin experiencing muscle weakness before age 5, according to the CDC.

APPROXIMATE AVERAGE YEARLY COST OF CARE PER PERSON:

\$23,000*

According to research published in the Journal of Managed Care & Specialty Pharmacy in 2017

WHAT IT COVERS: Medication copays, health insurance premiums and basic healthcare needs to children and adults

**The average out-of-pocket costs to individual patients may vary significantly based on factors such as insurance plan and medication regimen.*

Duchenne Muscular Dystrophy

Duchenne muscular dystrophy is caused by an absence of a muscle-related protein called dystrophin. Muscle weakness begins at an early age, and by the teenage years can affect the heart and respiratory muscles.

"It was really fairly easy to apply; I did it all online. Then I got a letter and I talked to someone on the phone who walked me through some information. The next thing I know I had the debit card."

— PARENT, DUCHENNE MUSCULAR DYSTROPHY FINANCIAL ASSISTANCE PROGRAM

FUND SPOTLIGHT

YEAR FUND LAUNCHED:

2012

PATIENTS ASSISTED IN 2017:

6,908

An increase of 2,465 patients from 2016 to 2017

APPROXIMATE AVERAGE YEARLY COST OF CARE PER PERSON:

\$23,000*

According to research published in Movement Disorders in 2010

WHAT IT COVERS: Copays for FDA-approved medications

**The average out-of-pocket costs to individual patients may vary significantly based on factors such as insurance plan and medication regimen.*

Parkinson's Disease

Parkinson's disease is a movement disorder that occurs when the brain does not produce enough dopamine. Symptoms include trembling in the hands, arms, legs, jaw and face and slowness of movement.

"It's been a miracle drug for him and we could have never have afforded it. He's got some of his life back, he really has. It's wonderful to know that TAF's there for people. Not just for us but for other people too."

— CHERYL AND DONALD, PARKINSON'S COPAY ASSISTANCE PROGRAM

FUND SPOTLIGHT

Multiple Sclerosis (MS)

MS is a disease that affects the brain and spinal cord and can be potentially disabling. The progression of disease, symptoms and severity of MS can vary significantly from person to person.

GOOD NEWS: In 2017 TAF reenrolled everyone who applied for MS coverage. That means that if someone received financial assistance from an MS program in 2017 and applied for 2018 coverage, they will continue to receive assistance for all of 2018.

"We got involved with TAF when the issue of cost came up. I remember we were sitting in our doctor's office when he told us the cost of the medication for a year. I don't think I will ever forget that. We were gobsmacked and not in a good way. Luckily, the doctor said, 'don't panic, because there are foundations that can help.'"

— KRIS AND RALPH, MULTIPLE SCLEROSIS COPAY ASSISTANCE PROGRAM

YEAR FUND LAUNCHED:

2009

PATIENTS ASSISTED IN 2017:

27,305

59% of patients have received assistance for 2 years or more;
40% for 3 years or more

APPROXIMATE AVERAGE YEARLY COST OF CARE PER PERSON:

\$50,000*

for someone with moderate disability from MS according to research published in the American Journal of Managed Care in 2016

WHAT IT COVERS: Out-of-pocket costs for supported medications or monthly health insurance premiums, travel and incidental medical expenses

**The average out-of-pocket costs to individual patients may vary significantly based on factors such as insurance plan and medication regimen.*

FUND SPOTLIGHT

Hereditary Angioedema (HAE)

HAE is a rare genetic disease that causes severe swelling in the hands, feet, face, throat and intestines. A swelling attack can be triggered by a trauma or stress, but often the cause of the swelling is unknown.

"Without TAF I wouldn't have any medication to combat the disease, which means I probably wouldn't be alive today. That's not a cliché. TAF has enabled me to go home and live my life. I get to live my life and enjoy it because I have access to medication."

— LAURA, HEREDITARY ANGIOEDEMA FINANCIAL ASSISTANCE PROGRAM

YEAR FUND LAUNCHED:

2012

PATIENTS ASSISTED IN 2017:

692

30% of patients received assistance for multiple therapies

APPROXIMATE AVERAGE YEARLY COST OF CARE PER PERSON:

\$410,000*

According to research presented at the AMCP Managed Care & Specialty Pharmacy Annual Meeting in 2018

WHAT IT COVERS: Medication copays, health insurance premiums and basic healthcare needs to children and adults

**The average out-of-pocket costs to individual patients may vary significantly based on factors such as insurance plan and medication regimen.*



“When I opened that door and allowed help to come in was when I really started to see there was life ahead and good things could still be there for me.”

-Eileen, Multiple Sclerosis Copay Assistance Program

Summary

The patient journey, and the ways in which financial distress plays into each stage of it, illustrates the importance of our mission at The Assistance Fund. We are there for patients when they are first diagnosed, and we stay with them as they pursue treatments and better outcomes. We allow those in need to focus on their health, rather than worrying about the potentially catastrophic consequences of high out-of-pocket costs.

We continue to innovate in how we deliver that support, enabling new and easier ways for patients to interact with us, provide us with the information we need to help them and receive the benefits we deliver. We also are deepening our relationships with other stakeholders, such as pharmacies and patient advocacy groups, to support patients and their needs.

It seems impossible to know what the future may hold for healthcare, but we anticipate more change. Insurers will continue to evolve benefit design. Policymakers will try to decrease costs, improve quality and ensure access. New therapies will continue to come to market, addressing diseases and conditions that have previously not had treatments.

As all that happens, we will be here to support the patients we can and ensure their journeys are as positive as they can be, so they can have the best health experience possible.



OUR DONORS WERE A CRITICAL FACTOR IN OUR 2017 SUCCESS AND WILL CONTINUE TO ACCELERATE OUR EFFORTS FOR THE 2018 FISCAL YEAR. WE ARE EXCITED TO SHARE OUR 2017 FINANCIAL HIGHLIGHTS.

For more detailed information and to view the Foundation's 990 tax return and financial statements in their entirety, please visit tafcares.org.

IN 2017, TAF RAISED



\$164M

IN 2017, TAF SPENT



\$126M

EXPENDITURES



95.3%

PROGRAM SERVICES | \$119,801,734
(directly associated with patient assistance)

3.8%

MANAGEMENT &
GENERAL SUPPORT | \$4,779,216

0.8%

FUNDRAISING | \$1,014,016

As of 12.31.17, TAF's net assets totaled \$118.7M. Since inception, 96% of TAF's expenditures has been directly associated with patient assistance. 3% has been for management and general expenses and 1% has been for fundraising.



give

Ways to Give

Making a donation is a simple and meaningful way to help us help people in need. All gifts to The Assistance Fund are tax-deductible.



ONLINE GIVING

Make a one-time or monthly gift at The Assistance Fund's website at www.taftcares.org/donate. You can also donate via our Facebook page by clicking on the donate button.



ONLINE SHOPPING

AmazonSmile (Search for "Assistance Fund, Inc.") and GoodshopGives allow shoppers to donate a portion of their purchases to The Assistance Fund.



MAKE A GIFT IN HONOR OR MEMORY

Make a gift to The Assistance Fund in honor or loving memory of someone at www.taftcares.org/donate.



LEGACY GIVING – A PLANNED GIFT

Leave a legacy and make a lasting impact by including The Assistance Fund in your estate. TAF accepts wills and bequests, charitable gift annuities and charitable remainder annuity trusts. Call 407.641.3024 for more information.

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