2018 IMPACT REPORT

# We Are Here for

The Assistance Fund



# MISSION

To provide critically or chronically ill individuals with access to advanced therapies through a continuum of services and programs, including education and financial aid.

# A MESSAGE FROM THE CHAIR

Each year, I am struck by the accomplishments of The Assistance Fund (TAF), an organization for which I am proud to serve as Board Chairman. TAF was founded 10 years ago, in 2009, thanks to the vision of two individuals and a small and dedicated group of board members. Ten years later, we are one of the preeminent independent patient assistance organizations.

My decision to join TAF's board was inspired by my personal experience of having a family member living with a serious medical condition. It opened my eyes to the financial and emotional challenges many individuals face when dealing with a serious or chronic illness, and the importance of having access to both informational and financial resources.

At TAF, it is important to us to make resources – whether financial, educational or otherwise – available to all who call. In 2018, we experienced a 30% increase in donations from the prior year, allowing us to provide more support and resources to patients. Since our inception, we have supported more than 78,000 patients – in 2018 alone, we assisted more than 36,000 individuals. The breadth of disease states we now cover has increased tremendously; we opened 14 new programs in 2018 and now offer more than 60 programs. We also expanded both our Medical Advisory Board and Board of Directors, which will help us continue to make well informed, people-centered decisions for the future of our organization. Our commitment to the people we help is the driving force behind all that we do.

Since our founding in 2009, we have held true to our vision to see the day when no person goes without medication because of an inability to pay. We will continue to pursue making this vision a reality by putting people at the center of what we do. Each day we work to remove barriers and help people access the treatment they need with dignity and peace of mind.

Sincerely,

Lawrence Hatch Chair, Board of Directors



"At TAF, it is important to us to make resources – whether financial, educational, or otherwise – available to all who call."

# A MESSAGE FROM OUR PRESIDENT AND CEO

New treatments and therapies come to market each day. While this innovation is encouraging and exciting, so many Americans are unable to access these treatments because of an inability to pay. As out-of-pocket costs continue to increase, TAF has become a crucial support system for those in need of medical-related financial assistance.

At TAF, we believe the people we support should have the same experience as those who can afford their out-of-pocket expenses, and we aim to provide this support to as many people as possible. To achieve this, we implemented several enhancements in 2018 to improve the services we provide. We developed a new IT platform to manage claims and enrollment, which gives us more independence and the ability to quickly and effectively assist patients and health care providers. The change also reduces administrative costs, allowing us to allocate more money directly to patient assistance. We also welcomed additional Patient Advocates and grew TAF's senior management team.

In 2019, we have a number of big changes and objectives in store:

**Connecting people with help:** We will continue to improve the experience of people we support and remove the barriers that prevent them from getting the treatment they need.

**Advocacy:** We will launch our Washington, D.C. office, where our newly formed D.C. team will spearhead advocacy and education initiatives. We need to ensure people know we are here and able

to help them during their time of need. We want to work with advocacy organizations to reach more underinsured people who need help accessing their critical treatments and identify the immediate and future needs of various patient populations.

**Transparency:** We are committed to being the most transparent 501(c)(3) independent patient assistance program in the country.

**Technology:** We will continue to invest in new technology to enhance and streamline our services. These changes will enable us to more efficiently distribute funding.

**Expanding our reach:** In 2019, we hope to expand our presence and activities across the U.S. We aspire to continue to connect with patients on a personal level to better understand their challenges and how we can provide them the best experience possible.

For all the accomplishments of this past year, we strive to achieve even more development, modernization and growth in 2019. Each year, we set new goals to bring us closer to our vision; we thank all of our donors for their continued generosity and support. I look forward to what we will achieve in 2019 and beyond.

Sincerely,

Mark P. McGreevy President & CEO



"At TAF, we believe the people we support should have the same experience as those who can afford their outof-pocket expenses, and we aim to provide this support to as many people as possible."



People assisted since inception in 2009



People assisted in 2018



**30%** Growth in donations

from 2017 to 2018

빨

Average number of claims submitted per patient in 2018



14 New programs opened in 2018



50 Number of states where we provided assistance in 2018, plus Washington, D.C. & Puerto Rico



60 Disease state programs









31,000+ Online chats handled in 2018



16 Conferences attended in 2018

# **OUR IMPACT**

2018 was a year of significant growth for The Assistance Fund. With a 30% increase in donations from 2017, we were able to open 14 new disease programs. And we provided assistance to over 36,000 patients. Read more about our 2018 impact.



# PATIENT FEATURE: WESTLEY, DUCHENNE

Westley was diagnosed with Duchenne Muscular Dystrophy at age seven. To some, this may seem like a devastating condition, but the diagnosis hasn't stopped Westley and his mother Jessica from enjoying life, maintaining a positive attitude and doing things as a family that bring them joy.

"Wake up every day with a smile on your face and don't look at the negatives," Westley says.

Westley is a Virginia native who just turned 16. He's an older brother and a leader at school and at home.



Westle

WESTLEY, DUCHENNE

"If Westley can wake up every day with a smile on his face, so can I."

- Jessica, Westley's Mom





others

Westley loves to spend time outside

Westley loves the water, warm weather and taking trips to the bay As the family chef, Westley is a leader, Westley is an avid animal Westley cooks for recently recognized lover, including his two his family at least for his ability to lead dogs and one cat once a week a team and motivate

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"From day one Westley has always asked, 'How do we fix this?' Ten years ago, there was nothing in sight. We have worked with several organizations to help advocate for a cure. I've gotten to sit on panels and speak to members of Congress. I do it for Westley. TAF has taken a huge stress off me because I know the money is there. With its support, we can focus on spending time as a family and continue to advocate on behalf of those living with Duchenne."

#### **MEET WESTLEY**

Westley was diagnosed at age seven with Duchenne Muscular Dystrophy, a rare disorder characterized by progressive muscle weakness. When Westley was in elementary school, he would ask his mother, Jessica, why he couldn't run and jump like his friends. Now, at 16, Westley is a vibrant, inquisitive teen with a positive outlook on life.

"Even though I look different, I'm still a normal human being," Westley says.

"And a genuinely nice person," Jessica adds.

And an avid cook. Westley is the family chef.

"My favorite thing is to cook," Westley says. "I love steak and crab. I make crab cakes a lot."

He's also a big fan of animals.

"We have two black labs named Bear and Uli, and a cat named Gryndoor," Westley says. "They get along pretty well."

Westley enjoys spending time with his aide, younger brother and mom, taking trips to the park and painting. "We paint anything – just what we see," he says.

#### **STRIVING FOR SUCCESS**

Westley's day pretty much looks like everyone else's. He wakes up in the morning and heads to school.

"I love history – that's probably my favorite subject," Westley says.

Not only did Westley finish his first year of high school with a 3.8 GPA, he received a "Golden Spear Award," which recognizes kids who are all-around good students. Westley's teacher says he got the award because he's a good student, he's diligent and does his work, and he's always willing to help lead a team and motivate a group.

#### **STAYING POSITIVE**

A working mom with two kids, Jessica says it can be hard to balance daily life. With TAF's support, she has been able to pay for Westley's treatment costs, without compromising on other financial decisions – like not having to cancel a family trip.

Westley is known for his big heart.

"When I can do something nice for someone, that really makes me happy," he says.

Living with a rare and serious condition can take a toll on one's emotions and outlook on life. Westley has harnessed what others may see as challenges and channeled them into motivation for change, compassion and resilience.

Jessien

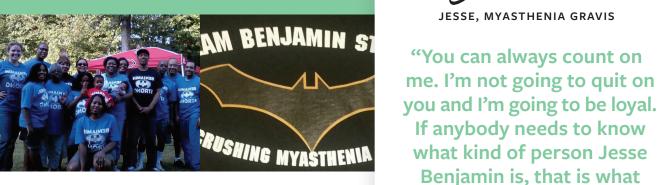
## **EXPRESSIONS OF GRATITUDE**

"The peace of mind in knowing that I will be able to afford my medication is priceless."



## PATIENT FEATURE: JESSE, MYASTHENIA GRAVIS

When Jesse received a diagnosis of Myasthenia Gravis, a friend told him about The Assistance Fund. After calling TAF and speaking with a Patient Advocate, Jesse instantly felt calmer knowing that TAF could help him get the financial assistance he needed. With TAF's support for his out-of-pocket medical expenses, Jesse has been able to stay active and spend time enjoying his favorite things hunting, fishing, working in the garage, playing with his dog and enjoying time with friends and family.



Jesse loves tinkering with his truck, a '94 Suburban

> Jesse calls cooking a "labor of love": sometimes he smokes meat for over 12 hours!



JESSE, MYASTHENIA GRAVIS

"You can always count on me. I'm not going to quit on

If anybody needs to know

what kind of person Jesse Benjamin is, that is what I would want them to know. You've got a friend in me as

long as you stick with me."

Beau, Jesse's dog, snores and licks a lot but is a great companion



For a pick-me-up, Jesse listens to some of his favorite music: rock and jazz



To relax, Jesse likes to read and take naps



"Anybody who is going through something, just don't give up. There were times I wanted to, but if I did I would've never gotten to this point. Sometimes it feels like such a long road and it'll never get better, but if you can improve 1%, that's worth it. You may not be where you were before but that's okay. Don't quit. Surround yourself with good people who really care about you."

Jesse

#### MEET JESSE

In 2014, Jesse was diagnosed with Myasthenia Gravis.

"I noticed my muscles were becoming weak and I wasn't feeling as strong. My strength level suddenly plateaued," Jesse says.

Over time his symptoms worsened, leading to hospitalization followed by a difficult recovery. Meeting Jesse today, there is no sign of the man who five years ago had to relearn how to walk, eat and swallow.

#### THE OUTDOORS IS CALLING

If you're looking for Jesse, you can probably find him outside. Nature is healing for Jesse. When he first got sick, Jesse spent most days indoors because he was nervous about being away from home and his medication. Jesse says the first opportunity he got to go outside felt like being reborn.

Jesse hunts, fishes, goes camping and spends most of his time "tinkering in the garage."

"Fixing something that was broken kind of represented how I felt because I was broken and then trying to fix myself," Jesse says. "So, if I could fix something and make it work again, I felt like I achieved something, even if I couldn't fix myself."

Jesse also loves grilling. "I love grilling and smoking meats, so that's my therapy," Jesse says. "A labor of love I call it, because sometimes it's a 12-hour cook so it takes patience and some love. But the end product is worth it."

#### **NEVER GIVE UP**

Jesse believes that while everyone may experience obstacles and challenges in life, how you face them is what defines you.

"If I had given up, I would have never gotten to this point. It feels like such a long road and like it'll never get better, but even if it doesn't get better to the point where you are the person you were before, if you can make even a 1% improvement then that's worth it."

Jesse considers himself lucky to have such a strong support system of family and friends. He says that you find out who your real friends are during times of need, especially when you don't know what turn life will take.

"Surround yourself with strong people," he says. "The people I call long-haul friends, who will be there not just when you're good but when you can't do anything at all."

This loyalty is something Jesse gives back to those around him.

"You can always count on me," Jesse says. "As long as you stick with me, you've got a friend for life."



## PROVIDER FEATURE: CHERYLANN GREGORY

Cherylann Gregory, RN, BSN, has over 35 years of experience in oncology nursing and is the founder and owner of the Specialty Pharmacy Nursing Network, Inc.

As part of Cherylann's work to educate patients and advocate on their behalf, she directs people to organizations that provide important patient resources, such as The Assistance Fund. Cherylann is committed to doing everything she can to

advocate for patients, including ensuring they know how to apply for financial assistance to receive the medical treatments they need.



Trains patients on self-administration of medication



Works with patients to understand the information needed to apply for TAF assistance



CHERYLANN GREGORY, NURSE & OWNER OF SPECIALTY PHARMACY NURSING NETWORK

"A typical day working with patients is a constant reward. This patient population has so many financial struggles. It is rewarding to be able to be an advocate for them and assist them with finding resources to help them financially."





Shares educational resources with patients about their disease Directs patients to advocacy organizations focused on specific disease areas

#### **PROVIDING CARE AND ADVOCACY**

Specialty Pharmacy Nursing Network, Inc. (SPNN) provides nursing services for patients with rare, ultra-rare, orphan and chronic diseases. Cherylann has seen the personal experiences individuals living with these diseases face paying for their treatments daily.

"Patients are asked to handle so much when they are first diagnosed and just starting a new therapy," Cherylann says. "They need an advocate to assist them with resources available to them and to direct them as to who to call for what. It is my goal to be as much of an advocate for them as possible."

Cherylann recently assisted a young man who only speaks Spanish and whose benefits had expired.

"Instead of just stopping his services, we had one of our Spanish interpreters call the patient and his aunt to discuss what information is needed to submit to The Assistance Fund for our nursing services to continue. Through our intervention, we were able to help keep his account current and he did not miss any doses."

#### WORKING WITH TAF

The out-of-pocket cost for many medications and related expenses can be very high, and because of that, patients may choose not to continue their treatment.

Cherylann became aware of The Assistance Fund when SPNN was hired to provide nursing services to teach patients how to self-administer medication. Not all of the patients qualified for self-administration, but some of the patients lacked home care benefits that would cover the needed nursing services. This is where TAF stepped in.

"Patients and family members are very grateful for the assistance; they feel that they would not be able to receive the proper treatment if it were not for this assistance they are receiving," Cherylann says. "These are patients who need a nurse to administer their therapy. Because the nurse comes to their home, it allows them to incorporate the therapy into their lives instead of the therapy taking over their lives."

With the financial support provided by TAF, these patients were able to receive in-home nursing services to administer their medication.

#### LEADING FULL AND PRODUCTIVE LIVES

Cherylann says the greatest gift is when her patients are feeling well enough to live full, active and productive lives because they are receiving the treatment and care they need.

"I have rescheduled patients with different nurses in other locations, so the patient can go on vacation or go back to college and still receive the therapy," she says. "Patients need this financial assistance. It allows them to continue with their normal lives, instead of the disease taking over their lives. The Assistance Fund is so user-friendly, and the staff is very knowledgeable and easy to work with. the assistance. They feel that they would not be able to receive the proper treatment if it were not for the assistance they are receiving."

Cherylana

#### **EXPRESSIONS OF GRATITUDE**

"They are making the world a better place, one patient at a time. I can't thank TAF enough."

Wayne





# PHARMACIST FEATURE: JOHN SEGINA

John Segina has been a group supervisor of Patient Financial Services at AllianceRx Walgreens Prime – one of the largest specialty and home delivery pharmacies in the U.S. – for a little over seven years. John started as a payment resolution supervisor before transitioning to the insurance department.

While on the job, John realized quickly that many people who take expensive specialty medicines to treat their chronic

or long-term condition struggle to afford their copays. He and his team often turn to The Assistance Fund (TAF) as a resource to patients.



Optimally manages financial services team in order to help as many people as possible



John

JOHN SEGINA, GROUP SUPERVISOR, PATIENT FINANCIAL SERVICES, PAYMENT RESOLUTION & INSURANCE VERIFICATION, ALLIANCERX WALGREENS PRIME

"The best thing about my job? In the end, we are helping people, whether or not we realize it. My team is a great group of people who truly care about the daily impact they make on patients' lives."





Previous experience in banking, sales and the mortgage industry

Assists with day-to-day operations of insurance department



Shares information about how to apply to TAF with patients Provides reassurance and respect when solving patient issues



"I noticed trends this year that I haven't seen since I started on this team. It is easy to take for granted that funding will always be available when patients need it; however, the reality is most nonprofits rely on donations to keep them running. When we see that a certain disease state is out of funding, we wonder how we will be able to help patients when they need it, how new patients starting a new drug are going to be able to afford the cost of the copay on their own."

John

#### HANDLING FINANCES

While there's no typical workday for John and his team, one thing remains constant: Each day they work to provide patients with the reassurance and help necessary to get the medicine they need.

"Every day, I help ensure each team member can get our referrals to the next stage for patient care in a timely manner," John says. "I collect daily feedback from them on the newest changes or obstacles within our realm of work. I also assist with the dayto-day operations of the insurance department, such as special projects, emails and escalations."

John has a broad understanding of the financial industry, having held positions in banking, sales and mortgage industries before joining AllianceRx Walgreens Prime. Now, his job allows him to use the skills and know-how he gained from working in finance to help people in need of financial assistance.

#### WORKING WITH TAF

John says his experience working with TAF has been positive. He says TAF's turnaround time allows patients to get their medications faster than other nonprofit organizations who offer similar services. "Our patients who receive TAF funding are very thankful when we can help them," John says. "Most of the time, if a patient requests funding and their disease state is open, they will get that funding. Very few get turned down for funding."

John says he was unaware of the impact TAF had on patients' lives until he became the supervisor of his department.

"It was amazing to discover how many patients received coverage through TAF," he says.

#### WORK THAT MAKES A DIFFERENCE

John says his team's work is rewarding because it makes a difference in people's lives.

"Patients mostly want reassurance, respect and the confidence that we will do whatever it takes to help address their concerns," he says. "My team and I are helping them get a medication that they otherwise wouldn't be able to afford. As long as we are giving 100 percent effort for every patient, I believe we are making a difference."



#### **EXPRESSIONS OF GRATITUDE**

'My life is completely different and for the better. Thank you sincerely, TAF, for helping me maintain my health. I, my family and friends are eternally grateful."



# THE PEOPLE ON THE OTHER END OF THE LINE

Our Patient Advocates are the backbone of our organization, working each day to provide individualized support to anyone who calls. On an average day, a Patient Advocate answers more than 30 calls and may participate in multiple online chats with patients, their caregivers and their health care providers. While every call and caller are unique, the commitment and passion of our Patient Advocates is steadfast. Our Patient Advocates pride themselves on being empathetic, patient and attentive. They are trained to put themselves in the caller's shoes to provide the best, most personalized experience possible.





"All of this will be on the paperwork but I'd love to go over it with you."



"I am happy to report you are conditionally approved – effective today."



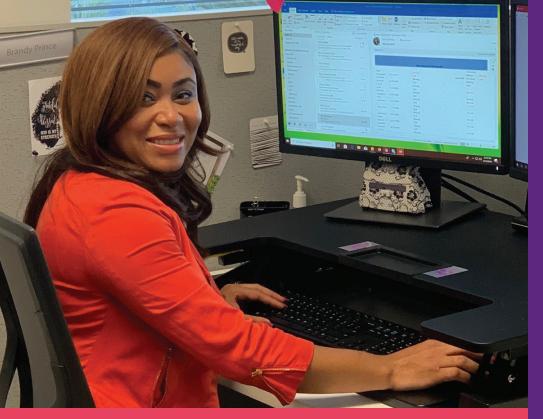
"That's okay. It's what we're here for."

"I can provide you with the member number and group number as well as the other information the patient will need."

"We did receive your application, and you have active coverage."

"We can step in and help you out. It's not a problem at all." "Thank you for calling The Assistance Fund. How may I help you todav?" "I'm going to go ahead and submit the reimbursement for March, April, and May."

"You're very welcome, and thanks for your time as well." "If you need any other assistance feel free to give us a call."





"As a Patient Advocate, I put myself in the patient's shoes by being attentive, showing compassion and providing education about our programs and self-help tools." Brandy

# **A DAY IN OUR CALL CENTER: BRANDY, PATIENT ADVOCATE**

# 8:30 A.M.

Brandy arrives at TAF and heads up to the fourth floor where she's greeted by her colleagues.

# 9:00 A.M.

The helpline is officially open!

# 9:10 A.M.

Brandy answers a call from a health care provider interested in enrolling a patient. Brandy lets her know that the best way to enroll a patient is through t<u>he online portal</u> at www.TAFcares.org.

# 10:15 A.M.

A patient calls wondering whether funding is available for the Pulmonary Hypertension Copay Assistance Program. Brandy informs the patient that the fund isn't currently accepting new patients, gives her additional resources, and suggests she check back as new programs can open at any time.

# 10:45 A.M.

A patient calls with guestions about how to fill out an application. Brandy helps clarify what needs to be done and how to return the application to TAF.

# 11:20 A.M.

A patient's spouse calls asking about a reimbursement. Brandy lets him know that the claim has been received and will be processed, and that he should check their debit card the next day.

# 12:45 P.M.

Ashley, a provider from a movement disorder clinic, calls inquiring about eligibility requirements for potential patients. Brandy shares information on what is required to apply for assistance and the status of the program they are interested in.

# 1:00 P.M.

A quick lunch break with the team.

# 2:30 P.M.

Brandy helps Mary, a patient, enroll in a program since she doesn't have a working computer. Brandy assists with enrollment and conditional approval and provides Mary with her new member number and information on when to expect more information in the mail.

# 3:35 P.M.

A provider from a national pharmacy chain calls worried about a patient who is no longer able to receive assistance from another organization. Brandy shares the web address for enrolling with TAF. She walks through how to apply and the information that is needed.

# 4:00 P.M.

Debbie, a patient, calls in to check on the status of a claim since the site of care had not received payment. Debbie is given information to check on the status of the claim so she can get additional details.

# 4:30 P.M.

Mary Lou, a patient, calls to make sure that TAF received a bill for an infusion. Brandy explains how to properly submit a claim for the copay amount.

# 6:00 P.M.

Phone lines close for the day.

# TOP FIVE PRIORITIES FOR 2019

In 2019, The Assistance Fund will celebrate its 10th anniversary. TAF's accomplishments over the past nine years has made an impact on the lives of over 78,000 individuals. As TAF moves into its 10th year, we will continue to help assist as many people as possible. By expanding our footprint and building out our technology services, we will be able to better serve our TAF community.



Assess needs and define patient advocacy initiatives



Diversify and strengthen donations



Grow and enhance IT structure



Provide assistance to more patients



Enhance TAF patient and provider experience

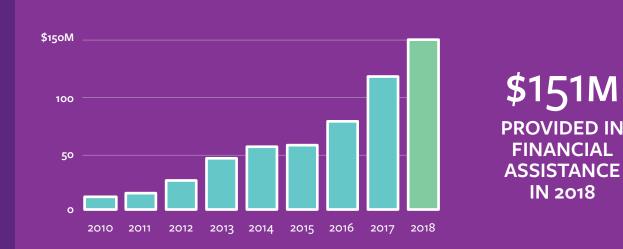
# 2018 FINANCIALS

Because of the generosity and support of our donors, we experienced a 30% increase in donations from 2017. Since our inception, we have provided \$600 million in financial assistance to patients. Each donation makes a lasting impact in the lives of the people we assist.

For more detailed information and to view TAF's 990 tax return and financial statements in entirety, please visit www.TAFcares.org.

# TOTAL DOLLAR AMOUNT OF ASSISTANCE PROVIDED SINCE INCEPTION:

# \$600М



THE ASSISTANCE FUND IN 2018 EXF

**EXPENDITURES IN 2018** 



\$154M PROGRAM SERVICES

\$5M MANAGEMENT & GENERAL SUPPORT

\$1M FUNDRAISING

# WAYS TO GIVE

Please support our mission! Your donation to The Assistance Fund is a simple and impactful way to help us assist as many people in need as possible. All gifts that go to The Assistance Fund are tax-deductible.



#### ONLINE

Go to www.TAFcares.org/donate and make a donation to TAF directly through our website. You can also donate in honor or loving memory of someone.



#### **BY PHONE**

To donate over the phone, please call (855) 845-3663 and ask to speak with someone from our Fund Development department.



#### **BY MAIL**

Download, print, and complete the Giving Form from the "Other Ways to Give" page on the TAF website and mail it to: The Assistance Fund 4700 Millenia Blvd., Suite 410 Orlando, Florida 32839.



# THROUGH SOCIAL MEDIA

Donate to TAF through our Facebook page by clicking the donate button at www.Facebook.com/AssistanceFund.



#### **THROUGH AMAZONSMILE**

When shopping on Amazon, type smile. amazon.com into your browser. Choose The Assistance Fund, Inc. as your charity and shop as you normally would. AmazonSmile will donate 0.5% of the price of your purchases to TAF.



## THROUGH PLANNED GIVING

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 (855) 845-3663 to learn more.

## USING GOODSHOP AND GOODSEARCH

Change the world while you shop with GoodShop. For every search, one penny or a percentage of your purchase is donated to TAF. It's quick and easy. Get started here: https://www.goodshop.com/nonprofit/assistance-fund.

#### **EMPLOYER MATCHING**

Double your impact. Many employers will match tax-deductible charitable contributions made by their employees, retirees, and employees' spouses. Ask your current employer about this opportunity today.

# LEADERSHIP

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