



# *Impact* **REPORT** FY20



Empowering families.  
Fighting Duchenne.

OUR COMMUNITY,  
**STRONGER** *together*



## OUR MISSION

Our mission is to extend and enrich the lives of individuals affected by Duchenne muscular dystrophy and other neuromuscular disorders.

We fulfill this mission by partnering with individuals and families through empowering educational programming, transformational direct service experiences, and by accelerating development of life-changing treatments.

### ABOUT THE COVER

In February, Jett Foundation staff traveled to Florida to help celebrate the arrival of a new accessible van for Alex Perez and his family, thanks to the Jett Giving Fund. Later in the year, we sadly lost Alex to Duchenne. Our community suffered many losses this year and we continue to dedicate our mission to those we have lost and honor their memory through our work.

## Letter from

### The Executive Director & Board Chair

Dear friends,

In spite of a challenging year, together we supported and lifted each other up. Thanks to the continued generosity of friends like you, Jett Foundation's community programs were more far-reaching and accessible than ever before.

With your help, in 2020 **we reached over 2,000** individuals and families impacted by Duchenne and other neuromuscular disorders by transforming each of our traditional programs into virtual opportunities, available from the safety and comfort of home. Programs such as Camp Promise, Jett Giving Fund, family support groups, educational workshops, and more reunited long-time friends and welcomed many new families, providing guidance and camaraderie through a difficult year.

Near the end of the year, we also announced the launch of a new arm of our Jett Giving Fund program—the Emergency Fund—with a mission to provide emergency assistance to families in need during the pandemic and beyond. In response, year-end giving increased by 40% compared to the previous year's appeal, dramatically increasing our ability to offer financial assistance to families who need it most. **Thank you.**

We are humbled by the overwhelmingly positive response we have received from the Duchenne and neuromuscular communities for helping to foster togetherness, provide assistance to those who need a helping hand, and, simply "being there" for our community in a re-imagined way.

Our goal is to continue to "be there" for and with our Duchenne community. Together—stronger than ever—we will keep fighting Duchenne muscular dystrophy and supporting families through our growing programs and innovative initiatives in 2021.

We—alongside Jett Foundation's board and dedicated staff—are hopeful for the year ahead and a return to safe togetherness.



**Eric Snyder**  
Executive Director



**Ellen Hanson**  
Board Chair



## OUR WORK *Transformed*

*Some of our highlights and success stories from throughout the year.*

Re-examined our work **to support 2,000+ individuals and families through isolation**, offering more virtual opportunities.

**Grew our reach** by making educational workshops more accessible to families through safe at-home webinars.

**Launched** a Facebook support group, 850+ members strong and growing.

**Pivoted** to virtual athletic fundraising events and raised over \$40,000.

**Fostered friendships** and fun by transforming our traditional Camp Promise experience into virtual weeks of camp.

Hosted **World Duchenne Awareness Day virtually**, sending 250 "WDAD Party Boxes" nationally to community members.



# EMPOWERING THROUGH *Knowledge*

## WORKSHOPS & WEBINARS

Our Family Workshops series is a cornerstone educational program for the Duchenne community that focuses on delivering pertinent information about Duchenne care, current and prospective treatments, resources, and hope to families nation-wide. Once COVID-19 hit, we quickly pivoted our educational programming virtually by offering webinars that continued safely equipping families with critical Duchenne resources and knowledge.

### 3 in-person workshops

supporting **35+ families** were hosted in MA, MS, and OR before the pandemic

### 22 webinars

were hosted over the course of eight months with **475+ participants** joining from **37 states**

### 15+ Duchenne medical professionals

from various disciplines and several certified Duchenne Care Centers presented during webinars

### 10 Duchenne-focused pharmaceutical companies

presented on clinical trials, research and the drug development pipeline

### 5+ Community Ambassadors

shared personal insights and experiences through parent perspective panels

### TOPICS INCLUDED:

- COVID-19 and DMD
- Isolation coping strategies
- Sex and relationships
- Independent living
- Smart home devices
- Navigating behavioral issues
- Respiratory health
- Understanding clinical trials
- and more

### 100%

of participants said the information presented was informative

### 89%

agreed they learned new and better ways to care for their child and family

### 93%

of participants reported feeling more up-to-date on clinical trials and research after watching a webinar

### 85%

shared that they felt more connected to the Duchenne community by participating

*"Thanks so much for this webinar. I have had many questions about respiratory care and the different stages as my concern for my grandson grows being at a different point than others. This has eased my fears that his care is appropriate for him."* - Sue



*"We just received the Jett Educational Care Package a few weeks ago and IT IS AMAZING! I only wish we'd gotten it at the beginning of our journey as it has already helped us so much!"* - Kriston

## EDUCATIONAL CARE PACKAGES

Our educational care packages provide crucial educational materials to newly diagnosed families, caregivers, teachers, and clinicians that are seeking more guidance on Duchenne information, support, and resources. Packages are provided free to community members and filled with materials ranging from support letters to navigational guides on care, health insurance and clinical trials.

### 123

care package requests through our website

### 100+

additional packages given to participants of Family Workshops and Porch Nites

### 72%

of those who requested packages had never heard of Duchenne prior to their child's diagnosis

### 76%

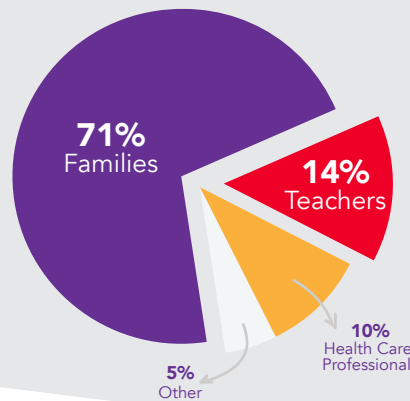
said that they would like to be connected with one of Jett's Community Ambassadors

## DAN AND DMD

While telling a child about a rare disease is never easy, Jett Foundation provides a free kid-friendly book, *Dan and DMD*, to help parents and guardians as they prepare to talk to their children about Duchenne.

In 2020, Jett Foundation mailed out **95+ copies** of the book to recipients in more than **32 states**.

### Who requested *Dan and DMD*?



On World Duchenne Awareness Day, the community was encouraged to read *Dan and DMD* with their families, friends, classmates, and communities. As a special treat, professional football player Ben Garland of the San Francisco 49ers joined us as a guest narrator of the book!





## MAINTAINING *Freedom*

### The Ojeda Family's Jett Giving Fund Story

The Ojeda family from California spends their favorite days taking trips shore-side, to the ocean or the lake, to swim and play together as a family. The water is an equalizer for the Ojeda family. Nine-year-old Billy lives with Duchenne muscular dystrophy, which is increasingly impacting his muscle function and ability to keep up with his sisters, Ily and Abby Rose. Chris, Billy's dad, says that playing in the water is Billy's chance to move freely and focus on being a kid. He also says that watching that freedom is one of the best things ever.

Billy was diagnosed with Duchenne after years of failing to meet physical milestones. As early as his one-year wellness check, it was clear he was physically far behind other children his age. After his diagnosis, his parents, Steffi and Chris, mourned the loss of the future they had envisioned and hoped for Little Billy, but they have found joy in the activities they can still do as a family. They also made a promise to each other and to Billy to focus on Billy's happiness and do what they could to stay ahead of Billy's needs.

"I never wanted him to not have the freedom, dignity, or control of being able to do what he wanted to do within

what is possible," said Chris. "We needed to stay ahead of him. We have been trying to keep that goal and our promise to him."

Without a safe, accessible vehicle, and partially due to mom Steffi's arthritis, going anywhere without dad Chris was challenging. Chris would have to lift and transfer Billy into their old vehicle to get to and from school and other activities. To make matters even more difficult, the family either had to keep his power chair at school all week or at home all week because it is so heavy and difficult to transport.

That is where the Jett Giving Fund came into play.

The Jett Giving Fund is a Jett Foundation program that helps families impacted by Duchenne obtain vital medical and accessibility equipment. Health insurance often don't—or simply won't—cover all specialized medical and accessibility equipment, such as scooters, shower chairs, ramps, rotational beds, accessible vans, and other essential items needed when dealing with a progressive muscular disorder. Families raise half the funds, or more, needed for a specific item, and Jett Foundation covers

the remaining costs and works with vendors to help bring families their much-needed equipment.

Chris had heard about the Jett Giving Fund program a while back, but at the time, they did not have a need for specialized equipment. As time went on, the need

**"The van was something we realized we needed as it became harder and harder to maintain Billy's independence and dignity while safely transporting him in his wheelchair."**

**- CHRIS, BILLY'S DAD**

dignity while safely transporting him in his wheelchair. Going to school was especially hard; Billy always said he felt like a baby and that the process was humiliating. This van came just in time."

With the help and support of their community, local organizations, and by spreading the word of their fundraising efforts at Billy's school and on social media, the Ojeda family raised half the funds needed for their \$70,000 accessible van. Jett Foundation covered the remaining half for the family, helping Billy and his family to receive their van amidst the global pandemic.

"The van is not just functional from point A to B, it allows Billy to fulfill his dreams. It allows him to live and be truly happy and have the best possible life he could. For us and for him, it is hope and dreams."

While the family celebrated the arrival of their van in the summer, the pandemic has put a pause on some of the fun adventures they plan to take.

"We want to drive to see national landmarks in the USA together as a family, like the Grand Canyon, where they have accessible paths," said Chris. "Even lots of local trips, like just going to the movies will be easier. We already have been able to go out as a family to enjoy socially distanced outdoor dining. It was such a treat for everyone."

grew more apparent as Billy transitioned to a powerchair and they began to adapt their home.

"The van was something we realized we needed as it became harder and harder to maintain Billy's independence and

## 2020 JETT GIVING FUND BY THE *Numbers*

**\$761,000**  
worth of equipment was  
gifted to families

**\$40,800**  
was the average cost of  
one gifted vehicle

**15**  
accessible vehicles  
gifted

**1**  
all-terrain power  
chair delivered

**1**  
hoyer lift  
installed

### SINCE LAUNCHING JETT GIVING FUND IN 2017, JETT FOUNDATION HAS GIFTED

**47** pieces of accessible equipment  
totaling over **\$1,700,000**

#### INCLUDING:

**39**  
accessible vehicles

**4**  
stair lifts

**2**  
power scooters

**1**  
hoyer lift

**1**  
all-terrain  
power chair

**1**  
rotating  
medical bed



# MAKING HAPPY <sup>virtual</sup> Campers

## CAMP PROMISE HANG OUT SESSIONS

At the onset of the pandemic, Jett Foundation’s Camp Promise staff quickly worked to host multiple hang-out sessions to help children and young adults, as many felt isolated and anxious at the start of the pandemic.

Hang-out sessions included fun activities such as movie nights, ghost stories, trivia night, live bug shows, virtual farm tours, and so much more!

**20+ events**  
over the course of camp’s “off-season” months of spring, fall, and winter

**200+ campers**  
cumulatively participated in these events

**26 states**  
were represented by participants, an increase to camp’s typical geographical reach

**70%**  
of campers were 18+

**84%**  
of campers were male

**82%**  
of campers were non-ambulatory

## CAMP PROMISE CONNECT

Keeping campers safe and connected, the team launched Camp Promise Connect with a goal of providing a virtual summer camp experience with the same high-quality programming delivered on-the-ground at camp. Camp Promise Connect sessions took place during our previously scheduled week-long sessions of Camp Promise and weekend sessions of Camp Promise Retreat. Campers, volunteers, and staff gathered safely over Zoom for a variety of fun and educational at-home activities.

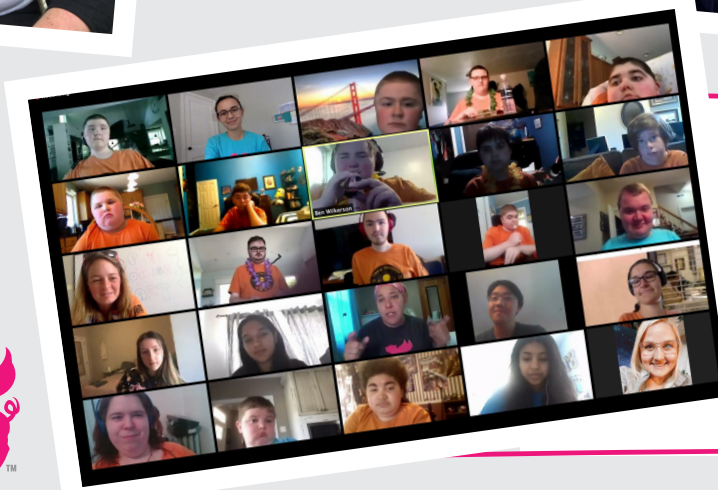
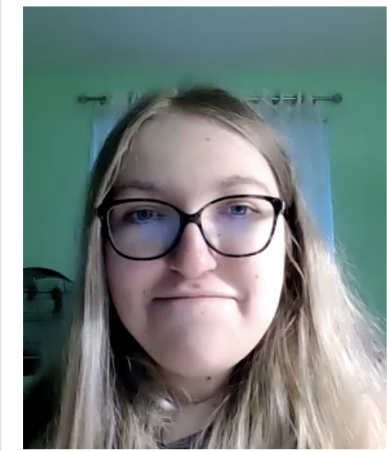
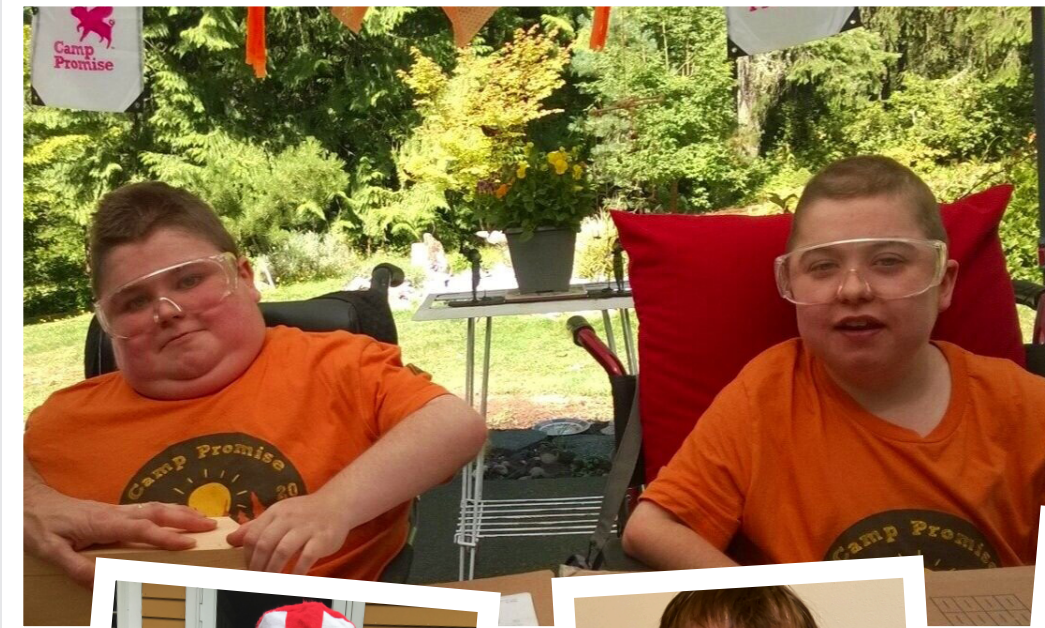
While the majority of campers had Duchenne and Spinal Muscular Atrophy, others served also had Friedreich Ataxia, Limb-Girdle muscular dystrophy, Becker’s muscular dystrophy, and Myotonic muscular dystrophy.

**161 campers**  
participated over the course of the three week-long sessions and two weekend sessions

**91 new campers**  
had never been served by Camp Promise before, that is over 50% of our participants!

**75%**  
of campers were male

**52%**  
of campers were over the age of 18, making them ineligible to participate in other camps



*“Even if there were no hugs, it was still the same excitement that comes with the first day of camp. Thank you so much for all of the amazing work it took to make Camp Promise Connect work. It really helped me to get a break in my quarantine blues and to reconnect with old friends.” - Darcy*





## SUPPORTING THE WHOLE *Family*

### COMMUNITY AMBASSADOR PROGRAM

Community Ambassadors are Jett Foundation's extra ears, eyes, and voices in the Duchenne community. Often parents, siblings, grandparents, or friends of a loved one impacted by Duchenne, these volunteers are advocates, educational resources, and pillars of emotional support.

- 17**  
active ambassadors  
volunteered throughout  
the year
- 15**  
states represented &  
served by ambassadors
- 275+**  
community members reached &  
supported through the program

*"Being a Jett Community Ambassador makes me feel like I am helping and contributing in some way. You often feel alone in this fight, but this program has helped me see that I am not alone and I can help others who need it."*  
- Jillian, NH Community Ambassador

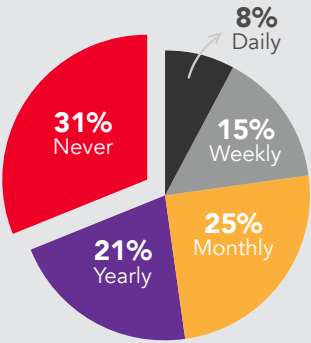


### SUPPORT FOR MOMS: PORCH NITE

Founded in 2018 by two Jett Foundation Community Ambassadors and moms of children affected by Duchenne, Porch Nite's goal is to bring love, support, and laughter to mothers affected by Duchenne across the United States. This national caregiver support program focuses on building stronger support systems for families affected by Duchenne in their local communities through story-telling, education, and grief-management.

- 3**  
in-person Porch Nite events  
were held before the onset of  
the pandemic
- 24**  
Virtual Porch Nite events  
were held between March  
and December
- 364**  
moms registered from 43 states,  
including 187 first-time participants
- 85%**  
of attendees were the primary  
caregiver for their child/children
- 96%**  
of moms agreed they would  
recommend Porch Nite to  
fellow moms
- 70%**  
strongly agreed Porch Nite provided them  
with support that they did not realize they  
were missing in their daily life

Before attending Porch Nite, how often did surveyed participants meet or speak with other moms of children impacted by Duchenne?



### SUPPORT FOR DADS: CHEERS & BEERS

Hearing from dads looking to make similar connections, Jett Foundation hosted a special Father's Day discussion in June featuring rare disease dad and biotech entrepreneur, John Crowley. After that event, a few of the dads from our Community Ambassador program launched their first support group meeting, Cheers & Beers, in August 2020.

- 71**  
dads from 26 different states  
registered and participated across  
three virtual gatherings
- 83%**  
of attendees were the primary  
caregiver for their child/children
- 78%**  
of participants shared they had not  
previously connected with a Duchenne  
parent in a supportive setting in the  
past month

*"Thank you for hosting Porch Nite!*  
I wish these were available 25 years ago when my son was first diagnosed at the age of six. Just meeting other moms that completely understand what my daily life is like is priceless! The exchange of knowledge and ideas will help so many in the community (including me!). I truly enjoyed meeting each one of you." - Lydia T.



# RAISING Awareness

## WORLD DUCHENNE AWARENESS DAY (WDAD)

This year, we transformed our one-day event into a week-long virtual awareness campaign and celebration with our national and international Duchenne community. During the week, we highlighted our “Stronger than Duchenne” community with Stronger Stories on our blog, had activities for families, hosted educational events to build awareness, and community events to foster connections. Participants were mailed “WDAD Party Boxes” which were fully equipped with supplies for activities and fun swag items to wear and use throughout the week’s events.

### 250 participants

joined us from 36 different states and two countries and included families, friends, clinicians, and industry partners

### 115 families

had never participated in Jett Foundation’s previous World Duchenne Awareness Day events

### 98% of participants

surveyed strongly agreed that they would participate in more virtual programming with Jett Foundation after their WDAD experience



*“This was alot of fun and it gave us some actionable items to do as a family as we raised awareness for Duchenne. We proudly have our Jett Foundation “Stronger than Duchenne” flag still on display.”*

# GO! FOR DUCHENNE *at-home*

In lieu of our in-person **Go! for Duchenne** events, this year our teams went virtual participating in our **Un-Run for Duchenne** or the **Virtual JettRide**.

## VIRTUAL JETTRIDE

### 20 cyclists

participated remotely, setting their own fundraising and mileage goals

### 4,500 miles

were logged over the course of the virtual event

### \$20,000

was raised

## UN-RUN FOR DUCHENNE

To ensure the entire community could get involved while staying safe at-home, we created a virtual challenge where any activity was fair game! Participants set their own goals and challenged themselves to get moving through traditional endurance activities and creative ones like TikTok challenges, tennis, yoga, hair cutting, cooking, and more.

### 17 participants

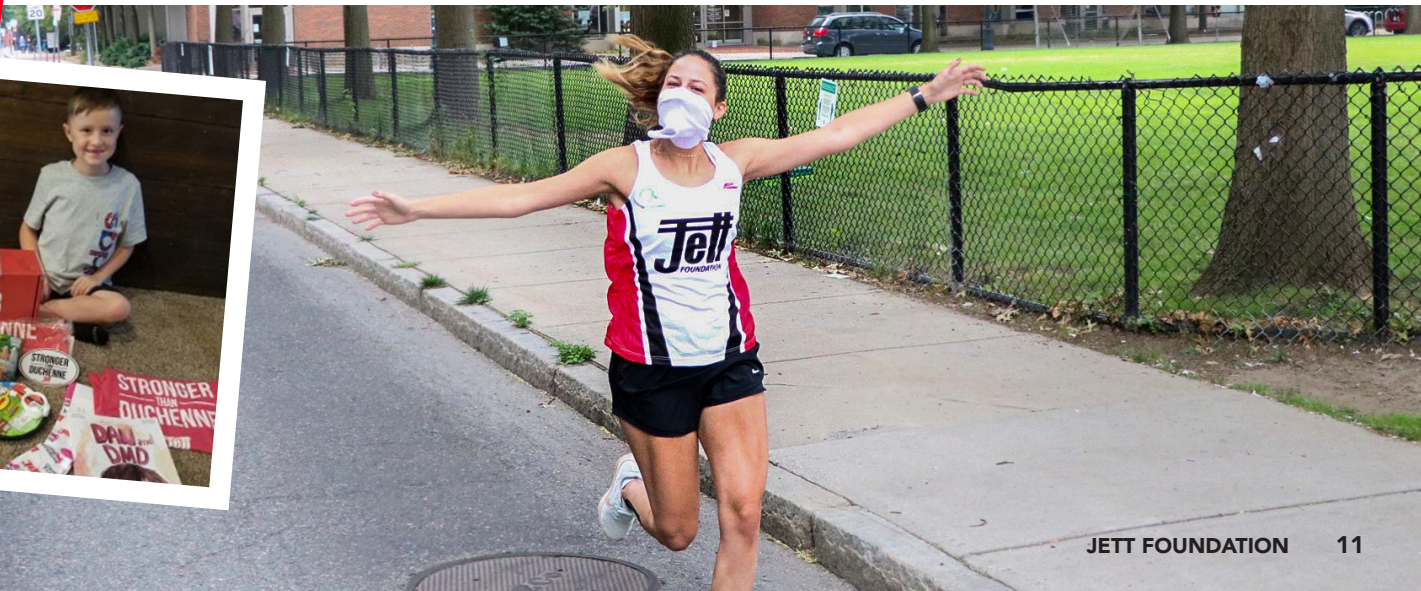
from the community got involved including families, industry partners, and Jett staff and board members

### 50% of participants

were new to our **Go! for Duchenne** teams

### \$21,000

was raised





# Thank you to our donors

Our donors are what makes it possible for Jett Foundation to empower families and fight Duchenne. Thank you to the people and organizations who provided a contribution of \$1,000 or greater during FY20 through financial gifts, in-kind donations, or peer-to-peer fundraising.

Amber Bates  
Andrea Torop  
Andy and Jessica Divin  
Angie Mackey  
Anthony Swanson  
Arizona Community Foundation  
Audentes Therapeutics Inc.  
Beth Baird  
Biogen  
Black Diamond Networks  
Boston Private Bank  
Brian Beaubien  
Casimir LLC  
Catabasis Pharmaceuticals  
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Loretta Sivret  
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Yulaunda Kiser



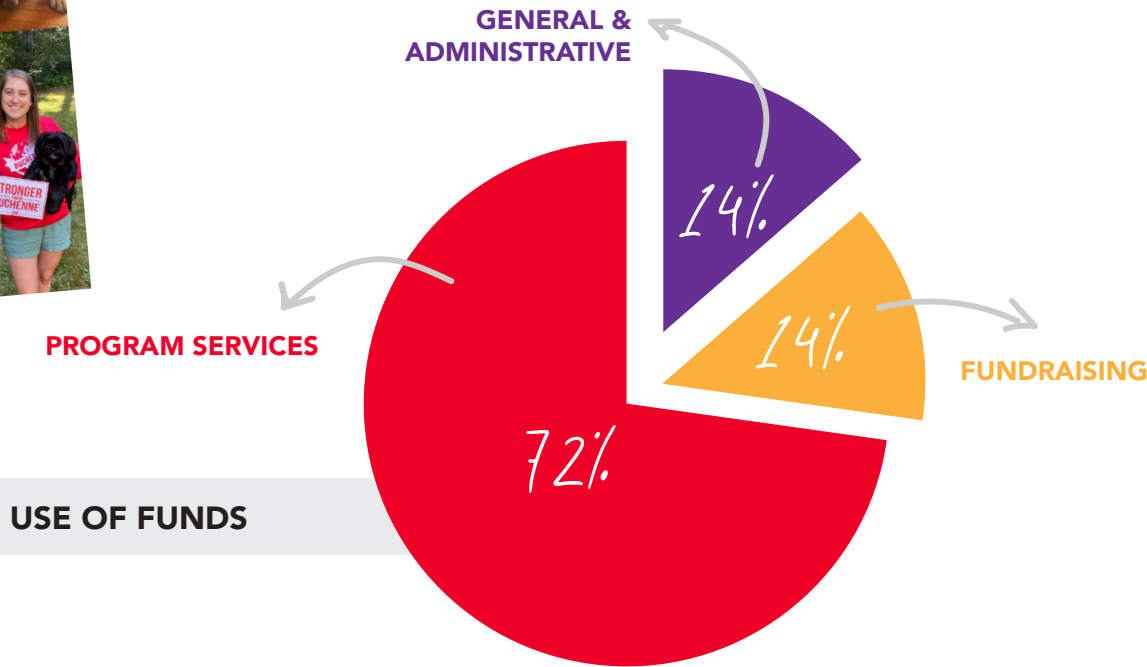
# FY20 Financials

## REVENUE

Grants	\$ 1,507,004
Individual Donations	\$ 131,408
Programs & Events	\$ 489,298
Other	\$ 116,140
<b>Total Support &amp; Revenue</b>	<b>\$ 2,243,850</b>

## EXPENSES

Program Services	\$1,341,026
Fundraising	\$271,212
General & Administrative	\$263,734
<b>Total Expenses</b>	<b>\$1,875,972</b>





# STAFF

**Maura Carroll**

Development Officer

**Gabriella Costa**

Director of Marketing and Communications

**Danielle Edwards**

Director of Community Engagement

**Shannon Healey**

Director of Program Development, Camp Promise

**Meghan Houston**

Asst. Director of Camp Promise

**Caitlin Hughes**

Development Coordinator

**Kelly MacGrath**

Finance Officer

**Eric Snyder**

Executive Director

# BOARD

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**Wendy Erler**, Alexion Pharmaceuticals

**Leo Robinson**, Wells Fargo Advisors

**Robert Stubbs**, Careport Health



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