



# 2018 **IMPACT** Report

Camp Promise - East 2018



Empowering families.  
Fighting Duchenne.

## 2018 YEAR IN REVIEW

Dear Jett Foundation family,

It is my pleasure to report on a wonderful year full of growth and development here at Jett Foundation. Over the course of 2018, our programs have expanded adding our **Jetting for Success** program, our **Dan and DMD** children's book gifting program and our work on a new study - **Your Voice: A Qualitative Assessment of the Impact of DMD on Families**. These programs have helped us reach hundreds of new families, bringing them into our Jett Foundation family and introducing them to our additional services for their families.

We are deeply thankful for the generosity of our supporters over the course of this year. Our team would like to extend a special thanks to the Flatley Foundation for their generous support of **Camp Promise**, Cure Dale's Duchenne for their major gift to the **Jett Giving Fund** and Perky Jerky, our national **Go! For Duchenne** athletic event sponsor.

This year, our **Go! for Duchenne** Gals for Cal triathlon team celebrated its 10th Anniversary and raised \$100,000 for our programs. Their strength and perseverance is an inspiration; we can't thank them enough. We are so grateful to all of this year's incredible athletes who took part in **Go! for Duchenne** teams across the country, including our very first team at the Rodman Ride for Kids in Foxborough, MA.



The support and investment of friends like you has made an incredible impact this year. In 2018, we provided the magic of **Camp Promise** to 88 campers, hosted 400 Duchenne patients, family members and caregivers at **Family Workshops**, and gifted over \$275,000 of accessibility equipment to families in need all over the country through the **Jett Giving Fund**.

At Jett Foundation, we believe in the power of education, the value of community, and the importance of hope. Each year, your commitment to our mission and to our Duchenne community helps us to bring these things and more to every family who has joined ours.

With gratitude,

Christine McSherry  
President & Jett's Mom

**FAMILY WORKSHOPS** This national educational program, one of our premier programs, brings clinicians, researchers, and families affected by Duchenne together to learn about standards of care, clinical trials, and other crucial information and resources in different cities each year.

Through these intimate meetings and in-depth post workshop surveys, we have learned more about the priorities and concerns of the Duchenne community and the educational gaps that we must strive to fill in 2019.



### 400+ participants

attended our 2018 Family Workshops in Hartford, Philadelphia, Richmond, Charlotte, Denver, Madison, Louisville, and Orlando.



### 25+ clinical trials

were presented at the workshops, giving families the tools they need to make informed decisions about their child's participation and treatment options.



### 50+ clinicians

presented at and attended Family Workshops across the country, educating and supporting families in their community.



*"Everyone needs some sort of support and education. This workshop was such a comfortable environment compared to just being in a doctor's office being told this information. You really realize that you aren't alone, others also are going through the same situation."*

*Corrienne Logan's Mom*



**CAMP PROMISE** Jett Foundation's Camp Promise allows children and young adults living with Duchenne and other neuromuscular disorders, of all ages and abilities, to participate in traditional summer camp activities, build confidence through age-appropriate programming that encourages them to step out of their comfort zone, and engage with others who live with neuromuscular diseases. **Nearly 500 happy campers have been served through Camp Promise since 2009 with the help of 800 volunteers.** This year, campers participated in fun and unique activities including:

- boating & boat racing,
- hot air ballooning,
- camp fires & smores,
- virtual reality roller coaster
- swimming & adaptive sports,
- petting zoos & reptile shows,
- luau dances,
- and so much more!

## 88 children & young people

affected by neuromuscular disorders participated throughout three week-long camps in Connecticut, Colorado, and Washington State in 2018.

## 30+ individuals

were on our waitlist in 2018. This is another area of unmet need that we plan to address in 2019.

## 60% of campers

we served in 2018 have aged out of all other camps.

**VOLUNTEER COMMUNITY AMBASSADOR PROGRAM** Our Volunteer Community Ambassador Program empowers parents to become advocacy experts and advocates for the Duchenne community. Parents trust parents, and we recognize that our community ambassadors can engage with and educate a broader and more diverse community than Jett Foundation's staff on our own due to geographic and socioeconomic challenges, cultural differences, and language barriers. Our Ambassadors provide real-time support, and guidance, as parents and family members to others in the Duchenne community.

In 2018, twelve Jett Foundation Ambassadors engaged with an estimated 75 families affected by Duchenne in the following locations:

- New Jersey,
- Pennsylvania,
- Connecticut,
- Louisiana,
- Florida,
- Illinois,
- Virginia,
- New Hampshire,
- Massachusetts,
- Tennessee,
- Rhode Island.

**JETTING FOR SUCCESS** This career and college coaching and peer mentoring direct service program prepares the young people we serve for meaningful secondary education and career opportunities.

## 9 participants

were accepted into the program in 2018.

## 2 participants

in the program served as a social media and a program summer fellow at Jett Foundation's office.

## 1 high school senior

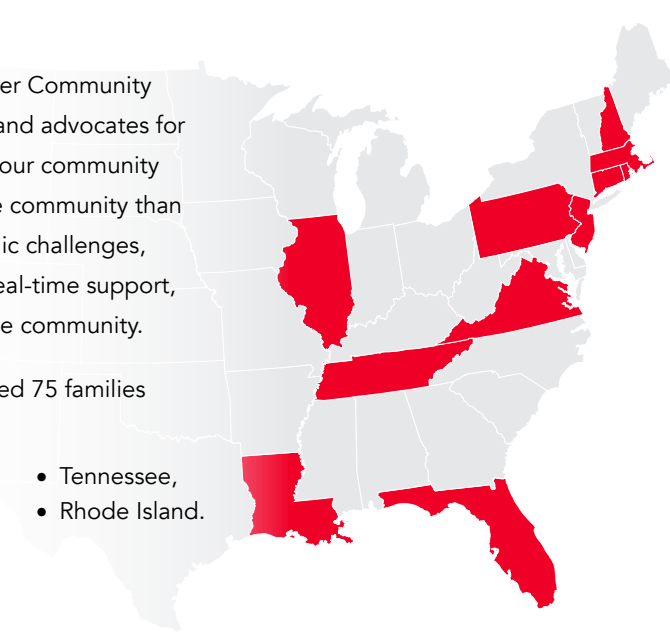
received two scholarships and started college this past September.

Camp Promise - East 2018



*"I had the best week ever and can't thank Jett Foundation and Camp Promise for providing this opportunity to individuals of all ages living with Muscular Dystrophy and related disorders. //*

*Colin, Camper*



**JETT GIVING FUND** The Jett Giving Fund assists families affected by Duchenne muscular dystrophy in purchasing unaffordable, but vital medical and accessibility equipment. To date, Jett Foundation has received 91 requests from families across the country whose children are in dire need of stair lifts, accessible vans, rotating beds and mattresses, scooters, and transfer equipment.

Since the program's launch, Jett Foundation's Jett Giving Fund has gifted 21 children and young people affected by Duchenne with medical equipment and items that improve their health and quality of life. The cost of the equipment gifted totals nearly \$600,000.

**In 2018 alone**, we have gifted the following to families across the country:



6

accessible vans



1

stairlift



totaling nearly  
**\$275,000**  
in equipment



Jett Giving Fund 2018

*"We needed a vehicle that would fit two wheelchairs and a family of six. It was impossible to go places as a family at one time because there was not enough room to fit safely in our old van. This van is going to make a huge difference in our lives."*

*Lisa, Ryan & Jack's Mom*



**DAN AND DMD** This is a beautifully illustrated and thoughtfully worded children's book that introduces readers to Dan, an upbeat kid who lives with Duchenne muscular dystrophy. Jett Foundation recognizes the challenges associated with discussing Duchenne, it's symptoms, and it's prognosis with children. We often hear from parents wondering how to explain a disease with such a devastating outcome to their child, and inquiring about this child-friendly informational tool that they can use to talk about Duchenne in their homes, classrooms, and communities.

### 520 requests

for **Dan and DMD** were received in 2018. 400 requests came from within the USA and 120 from different countries.

### 200+ families

are new to the Jett Foundation family and had not yet participated in any community programs or events.

### 42% of families

who requested a book indicated that their child receive a DMD diagnosis within the last three years.

**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.



36 Cordage Park Circle, Suite 328  
Plymouth, MA 02360

[info@jettfoundation.org](mailto:info@jettfoundation.org)  
p: 781-585-5566 | f: 781-585-5233

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