# INPOCTREPORT FY21





CELEBRATING 20 YEARS

of empowering families and fighting
Duchenne muscular dystrophy.

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## **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.

## **Letter from**

The Executive Director & Board Chair

In 2021, our organization celebrated an important milestone: Jett Foundation's 20th anniversary of service to the Duchenne muscular dystrophy community. For 20 years, Jett Foundation has been committed to children, adults, and families affected by Duchenne muscular dystrophy. What started as one mom's personal mission to save her son in 2001 is now a national organization delivering a robust array of transformational programs and services.

With your help, over these years, we have provided thousands of individuals and families with essential support and resources. From life-changing summer camp opportunities and accessibility equipment to family support groups and educational workshops, our community has had access to important programs that empower and foster independence.

In 2021, being faced with another pandemic year brought about a new set of challenges and unique opportunities to make an impact in Duchenne muscular dystrophy. We used this time to continue to perfect the uninterrupted delivery of our hybrid programs, ensuring the needs of our community were met safely with transformational programming and ready-to-access resources to help families at every stage of a Duchenne journey.

Our community helped us to launch a crucial new program providing financial support when families need it the most: in

unexpected, emergency circumstances. Friends like you helped us extend the reach of our Jett Giving Fundour financial assistance program for vital accessibility equipment. By adding an Emergency Fund branch to the program, we were able to assist families financially impacted by the pandemic and plan to continue this support for families experiencing unexpected hardships beyond this health crisis.

As we look to the future of Jett Foundation, and the return of our in-person programming in 2022, we thank you for the role you have played in Jett Foundation's ability to make a tangible difference in the lives of those living with Duchenne. We hope you will continue to be a part of our family as we look to the next 20 years of our organization's impact in the rare disease community.

You have played a key role in Jett Foundation's growth and transformation over the past 20 years. We are so grateful for your support and cannot thank you enough.

Sincerely,

Eric Snyder
Executive Director

Ellen Hanson Board Chair

## Looking back Then 3 New

## on a mission



### **10 STAFF MEMBERS**

& growing

Support for families in **NEW ENGLAND** 



Support reaching families

ACROSS THE NATION and beyond

Fundraising and raising awareness through

ONE ATHLETIC TEAM



#### **OVER 200 ATHLETES**

fundraising and raising awareness through *Go!* for *Duchenne* events

Efforts focused on

Delivery of over six core

RESEARCH AND FUNDING



TRANSFORMATIONAL PROGRAMS & SERVICES

**\$50,000**annual operating budget



**\$2,400,000** annual operating budget

20 years



Jett Foundation's Accessible Vehicle Fund Helps 25-year-old with Duchenne Get Behind the Wheel of His Own Vehicle

"You'll never be able to drive."

"A truck won't work for you."

"You will always have to rely on others for help."

"You'll never be independent."

These are just some of the things that people told 25-year-old Tyler Cooley when he expressed his dream of independently driving his own vehicle.

Tyler lives with Duchenne muscular dystrophy, a genetic disorder that causes progressive loss of muscle affecting many parts of the body including skeletal muscles, heart, and lungs. With the disorder's progression, Tyler has faced multiple bone breaks, undergone numerous surgeries, and persevered through various medical complications.

Through these challenges, Tyler attended college and completed his bachelor's degree. Just as he was wrapping up his program, he was offered a full-time job on the West Coast. The only problem: he was dependent on someone to accompany him in order to assist with loading his wheelchair and transferring him into the car.

"This whole situation made me realize that now, even more than ever, I needed to stay independent," says Tyler. "I needed a truck that would allow me to safely transport myself to necessary places, such as my work, without having to rely on someone else."

To others, driving a vehicle independently with a progressive neuromuscular disorder seemed impossible. But Tyler knew he could do it with the right kind of help. He applied to the Accessible Vehicle Fund, a branch of Jett Foundation's Jett Giving Fund program for

families impacted by Duchenne in need of reliable, safe transportation.

With help from his local community, Larry H. Miller Ford Mesa, 4 Jake's Sake, friends, and family, Tyler raised half the funds needed for his dream truck—one with modified controls and an accessible driver's seat. Once he met his goal, Jett Foundation covered the remaining costs, purchasing the accessible truck for him.

"To be told things like 'you'll never be able to drive' and 'you'll always have to rely on others for help' makes this moment even more special," says Tyler. "Never let someone limit you and show them you can defy all odds. This truck is truly amazing but what it represents is so much greater."

Since getting his truck, Tyler is driving himself safely to work every day and has even started planning road trips with his family and friends.

"I've always believed in miracles and this is truly one of them. Do not ever give up on your hopes and dreams to work hard to get wherever you wanna go," says Tyler's mom, Kathi Cooley. "We are SO incredibly thankful for each and every person who made this happen. This is EXACTLY what freedom looks like and his smile says it all. This truck represents so much regained independence."

"We can't wait to continue the mission of Jett Foundation and look forward to working with other families in the future to make amazing moments like these happen."

## Safe at Home

Illinois Family Moves into an Accessible Apartment with Helping Hand from Jett Foundation's Emergency Fund

In 2020, Jett Foundation expanded the Jett Giving Fund program to assist families experiencing unexpected financial hardship as a result of the COVID-19 pandemic. After hearing directly from families in our Duchenne muscular dystrophy community, the Emergency Fund arm of our program was launched providing timely financial assistance for necessities such as groceries, housing assistance, utility expenses or other unforeseen costs.

Raquel Coleman was looking for assistance with rent when she heard about Jett Foundation's programs through the Muscular Dystrophy Association and on social media.

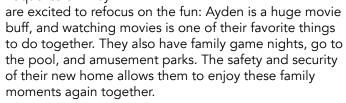
Raquel is a mom to a 10-year-old daughter and 13-year-old son Ayden, who lives with Duchenne muscular dystrophy.

After a difficult year, Raquel had been homeless for five months before applying to the Emergency Fund. Their unreliable housing situation made not only their normal routine more challenging, but also took priority away from crucial appointments for her son.

While trying to secure housing, Raquel and her family stayed at a relative's house. However, being on a second floor apartment became challenging for Ayden.

"It was super hard watching Ayden crawl up the stairs everyday, to get to the second floor. It literally broke my heart," she says. With Jett Foundation's help, now Raquel and her family are able to live in an accessible first floor apartment. Being able to have their own place to call 'home' now, has been life changing for Raquel and her family.

"We want to do as many things together," Raquel said. They



"I truly had no idea how generous Jett Foundation was going to be. I was not expecting this at all, I was completely taken back," said Raquel. "It has simplified our lives a lot. It has taken pressure off having to be in so many places at once."

## Jett Giving Fund by the numbers

### 14 families

accepted into the Accessible Vehicle Fund program, serving 20 total individuals with Duchenne

### \$800,000

total accessible vehicle cost for our 2021 program \$56,000

was the average cost of an accessible vehicle

### 15 grants

awarded through the Emergency Fund \$31,000 total emergency support granted to families

Established in 2017, Jett Giving Fund has helped transform the lives of countless families across the country with over \$2.5 million worth of accessible equipment and emergency assistance thanks to the generous support of individual donors, local communities, and major sponsors and community partners including Cure Dale's Duchenne, Sarepta Therapeutics, FibroGen, the Flatley Foundation, Ryan's Hope for a Cure, Joaquin Warriors, Michael's Cause, Kindness Over Muscular Dystrophy, and the Killian Family.



## Reinventing the Summer Camp Experience

Camp Promise Goes Virtual for a Second Year in a Row, Helping Campers Stay Connected

The Barkoskie family first heard about Jett Foundation during the FDA approval of Exondys 51. Mom Blake Barkoskie was amazed to see the community come together for that process and witness the power of grassroots engagement.

"Jett Foundation was a critical part of that process and the successful outcome. It was during that time we learned about Jett's programs for families," said Blake. "Camp Promise certainly caught our attention. My son, Will, always looked forward to summer camp, but Camp Promise offered so much more. Will attended his first Camp Promise-East session in 2018, and it exceeded his and our expectations."

When the family moved to Colorado in 2019, Will was delighted to learn there was another Camp Promise location nearby. "Camp Promise was one of the first things he asked about when we were moving and we were thrilled to discover the west location!"

Summers at Camp Promise brought joy not only to Will, but to his parents. A week of camp is so much more than just a week of fun; it means peace of mind for the Barkoskies, and so many other families and parents.

"As a parent, I know Camp Promise is going to create amazing experiences and memories for Will," says Blake. "Not only is it fun, but enables Will to feel a sense of independence and 'normalcy' that he should feel at his age. For that week (and much more thanks to the virtual programming), Will is surrounded by others that have

similar challenges but also is able to be a 'normal kid.'
That means everything to a parent. To see the joy in his face in the pictures and to hear him talk about his time a camp, brings such a sense of peace and contentment.
And as a caregiver, that week of respite is a game-changer, especially when you know his needs will be met in every way. Camp Promise is good for the soul... for everyone!"

The entire Barkoskie family was looking forward to a third summer of Camp Promise when the pandemic disrupted summer camp plans for organizations across the nation.



"Camp Promise Connect was a lifeline for our family as we continued to take precautions with regards to COVID."

Jett Foundation's Camp Promise program quickly pivoted, reinventing the delivery of summer camp in a way that was fun and engaging from the comfort and safety of home. Through off-season Hang Out Sessions, week-long Camp Promise Connect opportunities, and a few long-awaited in person Friends & Family events this past fall, campers were given the chance to safely come together. In both 2020 and 2021, Will capitalized on the opportunity to connect with his friends, and make some new pals, virtually through Camp Promise's various offerings.

"Camp Promise Connect was a lifeline for our family as we continued to take precautions with regards to COVID. Our family wanted to be very cautious during the pandemic which meant a lot of sacrifices," said Blake. "Camp Promise was so quick to pivot to the virtual activities. It really provided some levity and connection."

Will echoed his mom's sentiments saying "I really liked virtually hanging out and making friends... even though we all live in different places. Sometimes we would do art or have science experiments, but sometimes we just played games. It is always fun."

In the early fall, when COVID-19 cases were trending low, the Barkoskies joined Camp Promise's family weekend hosted in Denver. They spent the weekend reconnecting with camp friends at a Rockies game and a trip to the Denver Nature and Science Museum.

When asked if he planned to apply to camp in summer 2022, Will exclaimed, "My mom just told me Camp Promise is back and I cannot wait!"

Camp Promise is made possible by the Flatley Foundation, PTC Therapeutics, NS Pharma, Sarepta Therapeutics, Dunkin' Joy in Childhood Foundation, and Vertex.



## 164 campers

participated in our week-long, virtual Camp Promise Connect program

#### were brand new to Camp Promise

32% of campers

## 33% of campers

were over the age of 18, meaning they had aged out of all other camp opportunities

## **33 states** represented by campers in 2021

## 16 Hang Out Sessions

hosted year-round to stay connected

## **59 participants** at our in-person Friends &

at our in-person Friends 8 Family events in the fall



## **Supporting the Whole Family**

Jett Foundation Community Ambassadors and Virtual Porch Nite Events Help Bridge the Connection Gap for Families

Community Ambassadors are Jett Foundation's extra eyes, ears, 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.

Community Ambassadors have helped Jett Foundation to reach individuals and families virtually throughout the pandemic. In 2021, Jett Foundation welcomed 19 Community Ambassadors to the team from 17 different states. From licensed nurses and medical backgrounds to experienced fundraisers and educators, each ambassador brought unique perspectives and support for families to the table.

Erika Rome, who has a counseling background and now works as a special education teacher, shared what drew her to the role of Community Ambassador.

"My hope is that I can help newly diagnosed families," said Erika. "My son is seven, but I have been dealing with this diagnosis for six years. Many newly diagnosed families will have children close to my child's age and I think my experience and length of time since diagnosis puts me in a unique situation to help families with young children. I also have specialized training in dealing with ASD and behavioral issues. I would like to help families with IEP and

offer any help in dealing with ASD or any other behavioral problems."

This year, ambassadors also played an important role in Jett Foundation's annual Rare Disease Day event. Ambassadors Blake Barkoskie, Jessica Campbell, Diana Johnson, Laura McRitchie, and Jessica Rownd each shared their families' experiences navigating the challenges of Duchenne coupled with the impacts of the pandemic.

Jett Foundation's Community Ambassadors also help to plan and execute one of Jett Foundation's cornerstone support programs: Porch Nite.

Founded in 2018 by two Jett Foundation Community Ambassadors and moms of children affected by Duchenne, Perlita Hains and Dana Edwards, 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.

While Porch Nite began as an in-person gathering, throughout the pandemic, moms have been gathering virtually at Porch Nite sessions bi-weekly for what has

lovingly become known as "Mom Mondays." Each Porch Nite event is free and open to all moms in the Duchenne community.

66

## "Porch Nite was the biggest 'exhale' moment. You are with women that get it... truly get it."

While some sessions are open ended, oftentimes there is a clear topic to steer the conversation. In 2021, moms hopped on to talk about clinical trials, self-care, marital challenges, medications, transitioning, and more. Parents and guardians were also invited to participate in a Porch Nite "Book of Knowledge" pilot session. During the session, participants compiled important information regarding their child's medical condition and contact information in one safe space—their Book of Knowledge—for reference in case of an emergency.

"I've literally learned 98% of what I know about Duchenne from these moms and conversations that take place on Monday nights throughout the year," said Community Ambassador Jessica Campbell, who frequents the virtual sessions. "When one hurts, we all hurt. But don't be fooled, there is a lot of laughter that takes place. There's connections and friendships that happen because of Porch Nite. Porch Nite literally saved my life as a Duchenne mom!"

This past year, our ambassadors hosted 20 virtual Porch Nite sessions via Zoom, cumulatively welcoming over 200 participants from 37 states. Many moms were repeat participants, averaging six sessions throughout the year.

"Porch Nite was the biggest 'exhale' moment. You are with women that get it... truly get it," said Community Ambassador, Rosalie Callahan. "Everyone shares their opinions, advice, suggestions, and items that help them get through day-to-day."

## Community Ambassadors by the numbers

19

active ambassadors volunteered throughout the year

**17** 

states represented & served by ambassadors

300+

community members reached & supported through the program

## Porch Nite by the numbers

20

virtual Porch Nite sessions hosted in 2021

202

participants registered across the 20 sessions

**37** 

states represented by participants

94

parents and guardians participated in a special "Book of Knowledge" Porch Nite session



## **Spreading the Word**

Jett Foundation's Educational Programs Help Families Be Their Own Best Advocates

Building off the success of 2020's educational webinars, this past year Jett Foundation continued its Community Webinar Series. Our Community Webinar Series is focused on ensuring that the Duchenne community is better prepared for unexpected moments, challenging medical decisions, and difficult stages when on a Duchenne journey.

The series welcomed guest speakers from different disciplines and areas of expertise throughout the year's 19 webinars. Speakers covered a variety of educational topics including:

- Non-Verbal Communication and Assistive Devices,
- Positively Preparing for Clinic Day and Clinical Trials,
- Corticosteroids in Duchenne,
- Gastrointestinal Health Maintenance for Duchenne,
- Social Security 101,
- Exon Skipping,
- Understanding Duchenne and Genetic Mutations,
- Steroid Management and Emergency Situations,
- Advancements in Duchenne Drug Development and FDA Approved Therapies,
- And updates from pharmaceutical companies on their pipeline and clinical trials.

One parent shared just how meaningful and relevant the series was for her family.

"My son, husband, and I were extremely grateful to Jett Foundation for presenting this webinar. Our son, 25, is ready to proceed with a G-tube. Eating has become more of a chore than a pleasure for him. He tires easily and tends to need a lot of cough assist and suctioning with his meal times. We waited for this presentation before scheduling his procedure. We feel a lot more confident moving forward."



## "We feel a lot more confident moving forward."

Beyond webinars, Jett Foundation supported families and communities through the educational Welcome Packet program. Our educational Welcome Packets provide crucial educational materials to newly diagnosed families, caregivers at every stage of their journey, teachers, and clinicians that are seeking more guidance on Duchenne,

## 33% of individuals requesting WELCOME PACKETS

said they were looking for support in coping with their or their child's Duchenne diagnosis

.....

support, and resources. Thanks to the generosity of our program sponsors, packages are provided free to community members and filled with the following:

- Jett Foundation brochure and welcome letter,
- Support letters from the community,
- Health insurance, clinical trial, and classroom guides,
- Standards of care and medical durable equipment booklet,
- Dan and DMD children's book,
- PJ's Protocol Cards.
- and more.

In the past year, Jett Foundation collaborated with clinics to provide these packets to their patients. Over 100 packets were distributed across the UMass Medical School Clinic, San Diego's Rady Children's Multidisciplinary Neuromuscular Clinic, Children's Hospital of the Kings Daughter, University of Iowa's Children Hospital, Children's Health Dallas, University of Florida, and Atrium Health Neurosciences Institute-Neurology.

Our educational programs are made posssible by Astellas, Astellas Gene Therapies, Avidity Biosciences, Dyne Therapeutics, Edgewise Therapeutics, Entrada Therapeutics, Fibrogen, Genentech, Inc., Italfarmaco, NS Pharma, Pfizer Inc., PTC Therapeutics, Sarepta Therapeutics, Ultragenyx, and Vertex.

## Community Webinar Series by the numbers

### 19 webinars

held throughout the year

#### 11 webinars

were hosted by pharmaceutical companies presenting on their clinical trial pipelines

### 8 webinars

were educational in nature, featuring clinicians and medical experts

#### 700+

registrants across the 19 hosted webinars

### 300+

views on recordings of webinars post-event

### 82%

of surveyed participants rated the speakers' knowledge of their topic as "excellent"

### **52**%

of surveyed participants said the information presented was brand new to them

## Rising to the Challenge

Jett Foundation's Annual Rare Disease Event Goes Virtual, Welcoming Parent Panelists as they Share Challenges of Duchenne Through a Global Pandemic



Every year, Jett Foundation celebrates Rare Disease Day on February 28 by bringing together Duchenne industry partners, clinicians, individuals, and families impacted by Duchenne muscular dystrophy. Jett Foundation held its 4th Annual Rare Disease Day event virtually this year, welcoming over 200 individuals to our live panel discussion. The panel featured community ambassadors, Duchenne medical professionals, rare disease researchers, and more, each of which shared their personal stories about persevering through and overcoming challenges caused by COVID-19.

The event welcomed moderator James Valentine, Associate Attorney at Hyman, Phelps & McNamara. Special guests included Dr. Han Phan, Neurologist, Christine McSherry, Co-Founder of Casimir Trials, and Jett Foundation Community Ambassadors Blake Barkoskie, Jessica Campbell, Diana Johnson, Laura McRitchie, and Jessica Rownd.

Our speakers brought their unique stories to the table while sharing real-life scenarios, situations, and perspectives of experiences they have encountered over the past year due to the pandemic and Duchenne.

One ambassador, Diana Johnson, shared how the pandemic has impacted her family and her son's care during the call.

"The biggest impact on Jordan has been the change to the clinic/hospital setting," Diana said. "It's become a very cold, sterile environment. Many of the play-based therapy activities that he used to enjoy have been eliminated and it has become more strenuous to go to appointments."

The conversation delved into a variety of topics ranging from participating in clinical trials through the pandemic, handling remote work and virtual schooling, telehealth, and home infusions, finding community, and more. Receiving support and discovering independence through a Jett Foundation virtual direct service program was a common thread amongst each of the ambassador panelists' experiences.

When thinking about other silver linings of the pandemic, Diana said, "We have already experienced having our lives change overnight, how frustrating it is not to have answers to scary health questions, fear of the unknown, etc. Now everyone can understand to a degree how that feels, which may result in a greater empathy for the rare disease community and a deeper perspective of what we will continue to deal with even after the pandemic is over."

We would like to extend a sincere thank you to each of our speakers for taking the time to share their experiences through the challenges of the past year. Jett Foundation would also like to say thank you to our generous Rare Disease Day 2021 sponsors who made this day possible: Antisense Therapeutics, Astellas, Casimir, Dyne Therapeutics, Edgewise Therapeutics, FibroGen, Italfarmaco, JB's Keys to DMD, NS Pharma, Pfizer, Sarepta Therapeutics, Solid Biosciences, and Vertex.

200+ participants
attended the live, virtual event with
even more viewers streaming the
recording post-event

12 advocacy orgs joined us for the event

## 50+ industry partners

tuned in from our sponsoring pharmaceutical companies

8 clinicians joined us for the event

## Near or Far, the Community Comes Together

Jett Foundation Celebrates World Duchenne Awareness Day with Families and Partners Across the Nation

For the past several years, Jett Foundation has hosted an annual World Duchenne Awareness Day (WDAD) event of celebration and remembrance in the Boston area, the epicenter for rare disease research. Once again we were able to take the opportunity to broaden our celebration beyond our traditional Boston area event and engage with our families and partners all across the country virtually. And, to make things more fun, we shipped out 400 WDAD Party Boxes filled with fun "Stronger Than

**STRONGER** 

DUCHENNE

DUCHENN

Duchenne" swag and activities!

We loved seeing everyone get decked out in preparation for our WDAD events, whether it was showing us your best outfit, front yard, or car! In the morning, we kicked off our WDAD Celebration by moving our muscles with a live Zumba workout guided by Judi Perez.

In the afternoon, families got to grow with Jett Foundation by using our herb garden starter kits (a constant reminder that everyday your family grows we are here for you)! At Jett Foundation, we believe strength starts right at home with our families. What better way to come

together than around the dinner table? Community Ambassadors and Jett Staff shared some of their favorite yummy recipes in our Jett cookbook, sent to families to try and enjoy a meal together. After having so much fun cooking with the community, we were brought together for an educational webinar with Dr. Han Phan, pediatric neurologist. Dr. Phan shared updates on Advancements in Drug Development and FDA Approved Therapies in Duchenne, a great reflection of how far we have come and the strides we still have to make

In the evening, we got to Soar with Jett's Camp Promise. We rattled our inner feathers by grabbing our Bird Feeder Making Kit and experiencing the magic of camp with the Camp Promise team members Meghan Houston and Niki Benfield!

We were so impressed with the outpouring of support from not only our incredible community of families, but also our Duchenne industry partners who raised awareness alongside us by wearing Stronger Than Duchenne shirts and sharing team photos online.

Thank you to all of our generous sponsors for making this event possible: Antisense Therapeutics, Astellas, Astellas Gene Therapies, Avidity Biosciences, Dyne Therapeutics, Edgewise Therapeutics, Entrada Therapeutics, Fibrogen, Italfarmaco, JB's Keys to DMD, NS Pharma, PepGen, Permobil, Pfizer, RegenXBio, Santhera, Sarepta, Solid Biosciences, Stealth BioTherapeutics, The Assistance Fund, Ultragenyx, and Vertex.

Together, we raised awareness for Duchenne and our programs. All funds raised through our awareness efforts supported the programs and activities our community knows and loves like Camp Promise, Jett Giving Fund, Porch Nites, Family Workshops, and more.

If you joined us, thank you! Your participation is what made this year's World Duchenne Awareness Day amazing and we are so grateful!

400

World Duchenne Awareness Day Party Boxes mailed out across the nation 66

"This was a lot 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 WDAD flag still on display."



## Gals for Cal Team Compete in its 13th Max Performance Title 9 Triathlon Benefiting Jett Foundation

This year, Jett Foundation's Go! for Duchenne athletic fundraising initiative welcomed athletes at four different events throughout the year: an at-home 20th Anniversary Challenge, a Pennsylvania JettRide, the Falmouth Road Race, and the Hopkinton Title 9 Triathlon.

Sunday, September 12, 2021, marked the Gals for Cal's 13th annual Max Performance Title 9 triathlon in Hopkinton, MA raising funds and awareness for Duchenne muscular dystrophy and Jett Foundation.

The Gals for Cal triathlon team formed in 2009 with one mom. Cindy Quitzau and her son, Cal, who was diagnosed with Duchenne 13 years ago. She wanted to challenge herself and challenge Duchenne while raising funds and awareness for Jett Foundation and the families we serve.

The Gals for Cal team has grown from 10 friends and family that first year to well over 150 women over the past 13 years. This was a very special year to be a Gal, as Jett Foundation celebrated its 20th anniversary and Cal celebrated his 20th birthday in November. The Gals have expanded from one mom honoring her son, to a national community of women impacted by Duchenne. Race day was full of emotions as each Gal crossed the finish line, and the "Go Gal!"

cheers could be heard for hours.

Alongside 40 gals, this year, eight moms in the Duchenne community raced and/or raised funds in honor of their sons impacted by Duchenne: Cindy Quitzau, Amanda Becker, Lisa Shortlidge, Kristen McGourty, Michelle Parker, Stacey Santiago, Lori Safford, and Annie Ganot.

"This was the 13th Gals for Cal triathlon and what a day it was," said Cindy Quitzau. "Thanks to dear friends of mine who came up with the idea back when Cal was diagnosed with Duchenne, this incredible event has continued year after year ever since with astounding support! We are proud to continue to race each year in support of Jett Foundation's impactful programs."

The Gals for Cal's dedication to the Duchenne community has resulted in nearly \$700,000 raised since their founding, which has provided vital support to Jett Foundation's mission of improving the lives of people impacted by Duchenne. This year alone, the team has raised over \$40,000 in support of Jett Foundation programs like our summer camp for kids and adults impacted by neuromuscular disorders, their financial assistance programs for emergency help and accessible vehicles, educational programming,

and more. A big contributor to this success: our team sponsor, Solid Biosciences and the company's cofounder, Annie Ganot.

For the past several years, Annie has recruited her friends and family near and far, and this year she has also welcomed 15 of her colleagues from team sponsor Solid Biosciences, where she serves as Co-Founder, VP, and Head of Patient Advocacy.

"I am incredibly proud to be a Gal and participate in honor of my son, Eytani, for my 6th year and to be joined by so many members of the Solid community at this year's race," said Annie. "The awareness and financial support that has been raised by the Gals over the years is vitally important to further Jett Foundation's efforts to improve the quality of life for all patients living with Duchenne. Solid is a proud supporter of the Jett Foundation, and we are thrilled to continue our support through the Gals

This year's Go! for Duchenne teams were sponsored by BayCoast Bank, Bob's Discount Furniture, Eastern Bank Charitable Foundation, EOS, Solid Biosciences, Shea Concrete Products, Inc., and The Yale Charitable Foundation.

## Thank you to our donors

Glenn Drong

Joe Edelman

FibroGen, Inc.

**EOS-USA** 

Dyne Therapeutics

Foundation

Eastern Bank Charitable

**Edgewise Therapeutics** 

**Entrada Therapeutics** 

The Fairhope Store

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 FY21 through financial gifts, in-kind donations, or peer-to-peer fundraising.

Sondra Alvey Chris Andrews **Antisense Therapeutics** Astellas Gene Therapies Astellas Pharma **Avidity Biosciences** Beth Baird Daniel Barrett BayCoast Bank Andrew Bennett Best Ventures, LLC Bob's Discount Furniture Charitable Foundation, Inc. Kirandeep Boparai Scott Boyd

Garrett Buras Phillip Burnett Cabbyshack, Inc. Scott Callahan Laura Campbell Maura & Roger Carroll Jay Cashman Casimir LLC Cooley Family Crowley Family **Custom Construction** and Design, Inc. CustomInk LLC Ashley Damon Robin Desmarais

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Kathleen Knoble Becky Levin Liberty Rent Rebekah Loper Melissa Maasjo MacDonald-Miller Craig Martin Benjamin McKee Bob and Carolyn Moss Brian Mulcahy Brian Nicholoff NoBull Reviews Northeastern Line Chapter, NorthPoint Development, LLC NS Pharma, Inc. Red Nucleus Jeananne Oliphant Pam Orosco P&G Keene Electrical Rebuilders LLC Ronald Pace PepGen Inc Permobil Foundation Pfizer Inc. PTC Therapeutics Quincy Mutual Fire Insurance Rochelle Ragih Bernard Reynolds Cheryl Robinson Rockland Trust Charitable Foundation

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Sarepta Therapeutics, Inc.



## FY21 Financials

#### REVENUE

Ryan's Hope for a

Cure Foundation

Santhera Pharmaceuticals, Inc.

**Corporate & Foundation Donations** Individual Donations **Programs & Events** Other

**TOTAL SUPPORT & REVENUE** 

#### **EXPENSES**

**Program Services** Fundraising General & Administrative

**TOTAL EXPENSES** 

\$ 1,489,853 \$ 322,006 \$ 318,301 \$ 2,130,160

\$ 1,237,131

\$ 624,386

\$ 628,884

\$ 122,657

\$ 2.613, 058

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Eric Snyder, Executive Director

**FINANCE & HR** 

Kelly MacGrath

**PROGRAMS** 

Niki Benfield

Danielle Edwards

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