

JETT FOUNDATION



THE JETT GIVING FUND INFORMATION AND SPONSORSHIP PACKET

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*The Jett Foundation (04-3563445) is a registered
501c3 organization recognized by the IRS.*



A Letter from Jett Foundation’s founder and Executive Director, Christine McSherry:

In 2001, after learning the news that my then five-year-old son, Jett, was suffering from Duchenne muscular dystrophy, a rare disorder that would soon rob him of his ability to walk, lift his arms, and breath, my community and I started a non-profit organization called Jett Foundation, dedicated to saving his life and the lives of children like him, and to meeting the unmet needs of the Duchenne patient community.

Since then, we’ve raised over \$15 million for research, educated people around the world about Duchenne, expanded the realm of possibilities for hundreds of campers at Camp Promise, and advocated for policies that expedite drug development. We also saved Jett’s life, as Jett is part of a small population of Duchenne patients amenable to the first FDA approved treatment.

However, Jett Foundation’s work is not even close to being finished. Our accomplishments are simply a testament of how one village can unite to help one child, which is why I am writing you today.

We hope that you can help us meet yet another unique unmet need in the Duchenne community through supporting the **Jett Giving Fund**, Jett Foundation’s newest program. Families stricken by Duchenne are living an unimaginable nightmare. Their child is experiencing an unstoppable decline in function, and every year they age brings another certain loss of independence, self-confidence, and quality of life. The economic strain associated with Duchenne only serves to intensify that heartache as scooters, handicap accessible vans, and hospital beds become the new normal. The **Jett Giving Fund** aims to alleviate the financial hardship of family’s affected by Duchenne who need specialty adaptive and medical equipment often not covered under insurance to keep their kids independent and comfortable. **Jett Giving Fund** matches the fundraising efforts of participating families and buys the pieces of equipment they need when they reach their fundraising goal.

I understand the impact this disease has on their families and the overwhelming sense of frustration associated with watching your child decline, because I have lived it. I believe that **Jett Giving Fund**, with your help, can make a significant impact on the lives of those struggling to remain independent and “normal” for a little while longer.

A sponsorship package is enclosed. I hope you consider partnering with Jett Foundation to give the tangible gift of independence back to families in your community affected by Duchenne.

Sincerely and with much hope,
Christine McSherry (Jett’s mom)





The **Jett Giving Fund** only launched in February 2017.

But as you can see below, the need is overwhelming.

The following stories are only a small portion of the requests Jett Foundation has received to date.

“My son stopped walking 7 years and today cannot even sit down if it is not with help, his knees are contracted and he needs assistance for all the daily things of the life like dressing itself, bathing, for its physiological needs, spending it from the bed to the chair and from the chair to the bed, every morning begins a battle for jumping these barriers and the biggest the fact is that there is no treatment and its genetic mutation is of the exon 10 and 59, neither about which nor study I could have known, its heart began already with a dilation of the left ventricle and the fact is that skylight the heart also is a muscle. Every day we request for a cure to this sad illness that is debilitating it and simultaneously trying to take the life with happiness and a lot of hope.”

2/2/2017

“I have 2 boys with DMD who are 14 and 11. One is in a wheelchair full time, the other uses a scooter for long distances and for school. We had a very hard time getting the wheelchair approved from the insurance company. We are in need of a handicap van. We just remodeled our house to make it handicap accessible, which is wonderful. Now we are in need of the van and do not have the money to purchase one. The boys are picked up for school by bus, but once they are home we can not go anywhere because we can not bring my 14-year old in a wheelchair anywhere. Please let me know if there is anything you can do, and if there is anything else you need to know”

2/5/2017

“My son is 13y/o and was diagnose with Duchenne Muscular Dystrophy own a power wheel chair but we can't move it out of the house since we don't own an accessible vehicle. I was reading about the program Jett Giving Fund and that bring me some hope in order to pursue to get an accessible van.”

2/18/17

“Hi, I was wondering what we would need to do to start an application? Our son is 7 (8 next week) with DMD. He's struggling more and more with walking; we have started raising money for an accessible van (\$5,400 so far). We have an electric wheel chair but no way to transport so he often is stuck using his manual chair and us pushing him when he can't walk. Someone wrote me and told me about you guys. Thank you so much for your time!”

2/21/17



Jett Foundation established the **Jett Giving Fund to assist families affected by Duchenne muscular dystrophy in purchasing medical equipment often NOT covered by insurance providers.**

What is Duchenne? Duchenne is a progressive neuromuscular disorder that causes a loss of motor, pulmonary, and cardiac function, and premature death. It affects every 1 in 3,500 live male births and some females. Duchenne has no cure. Children with Duchenne are born seemingly healthy and decline over time, usually losing their ability to walk around the age of 12 and succumbing to the disease in their early to mid-twenties.

What is Jett Foundation? Since it's founding in 2001, Jett Foundation has remained committed to identifying and meeting the unmet needs in the Duchenne patient community. We have raised over \$15 million for research, educated people around the world about Duchenne, expanded the realm of possibilities for hundreds of campers at Camp Promise, and advocated for policies and legislation that encourage innovation in rare disease and the development of safe and effective therapies to treat Duchenne.

Why is the Jett Giving Fund so important? Currently, there are over 1,000 Go Fund Me pages set up by family's affected by Duchenne struggling to afford specialized medical and accessibility equipment that helps keep their kids more comfortable, independent, and "normal" as they age and their disease progresses. While one would think that insurance providers help patients with these costs, they often only cover the bare minimum or nothing at all. Handicap accessible vans can cost between \$50,000 and \$100,000, and rotational medical beds and mechanical arms in the tens of thousands. Items like these allow patients the everyday experiences such as going to the mall with friends, feeding oneself in the cafeteria, and traveling to medical appointments.

How does the Jett Giving Fund work? Jett Giving Fund applicants must raise at minimum, 50 percent of cost of the item they need for the general Jett Giving Fund program. Then Jett Foundation, through the support of generous corporate and individual donors, will match the remaining 50 percent and purchase the piece of equipment the family and patient needs.

How can you help? Enclosed is a sponsorship/in-kind partnership agreement. If your company or organization is interested in sponsoring the Jett Giving Fund with a monetary sponsorship agreement, or becoming an in-kind partner by providing an in-kind donation towards a particular item that patient(s) affected by Duchenne need, please fill out the agreement below.

Examples of items that the Jett Giving Fund can help provide:

- Handicap accesible vans
- Hospital beds
- Mechanical arms
- Scooters
- Shower chairs
- Power chairs
- Stair lifts
- Service dogs
- Rotational beds
- Beach chairs
- Power soccer wheelchair
- Pressure relieving air mattress

Sponsorship/In-Kind Partnership Levels

Freedom Sponsor/In-Kind Partners ♥ \$75,000 +

- Presenting sponsor at our Annual Shine a Light Gala
- The lead sponsorship at the Annual Jett Golf Classic
 - See package for details
- Acknowledgment in our monthly newsletter
- Corporate logo and name recognition on website & First Giving page
- Brand inclusion in all program promotional materials

Liberty Sponsor/In-Kind Partner ♥ \$50,000

- Sponsor at the Annual Shine a Light Gala
- Sponsor at the Annual Jett Golf Classic
 - See package for details
- Acknowledgment in our monthly newsletter
- Corporate logo and name recognition on website & First Giving page
- Brand inclusion in all program promotional materials

Achievement Sponsor/In-Kind Partners ♥ \$20,000

- A complimentary foursome at our Annual Jett Golf Classic
- Acknowledgment in our upcoming monthly newsletter
- Corporate logo and name recognition on website & First Giving page
- Brand inclusion in all program promotional materials

Independence Sponsor/In-Kind Partners ♥ \$10,000

- Acknowledgment in our upcoming monthly newsletter
- Corporate logo and name recognition on website & First Giving page
- Brand inclusion in all program promotional materials

Ability Sponsor/In-Kind Partners ♥ \$5,000

- Corporate logo and name recognition on website & First Giving page
- Brand inclusion in all program promotional materials

For verification of Jett Foundation's 501c3 contact:
jettgivingfund@jettfoundation.org or visit jettfoundation.org.

Sponsorship/In-Kind Partnership Agreement

Sponsorship/In-Kind Partnership Name: _____
(as you wish the name to appear in program publicity)

Company Name: _____

Address: _____ City: _____ State: _____ Zip: _____

Contact Name: _____

Phone: _____ Fax: _____

Email: _____

Sponsor/In-Kind Partnership Level:

Freedom Sponsor/In-Kind Partnership..... \$75,000 +

Liberty Sponsor/In-Kind Partnership \$50,000

Achievement Sponsor/In-Kind Partnership \$20,000

Independence Sponsor/In-Kind Partnership \$10,000

Ability Sponsor/In-Kind Partnership \$5,000

I/We are unable to participate at a sponsorship or in-kind partnership level but please find the enclosed tax-deductible donation of \$ _____

If participating in an in-kind partnership, also complete in-kind partnership donation form on pg. 6

Sponsorship Payment Options

I have enclosed a check payable to Jett Foundation in the amount of \$ _____
(Please make check payable to the Jett Foundation)

Please charge my credit card \$ _____

VISA ___ MC ___ AMEX ___ OTHER ___

Card # _____ Exp. Date _____ CSC Code _____

Name (as it appears on card): _____

Signature _____

Thank you for your support!

If the Jett Giving Fund no longer exists, all donations will be applied to further the general charitable mission of Jett Foundation.

Jett Foundation In-Kind Partnership Donation Form

Date (s) of contribution _____

Quoted Price of Item/Equipment _____

In-Kind Donation Amount _____

Final Price of Item/Equipment _____

(final price invoiced to Jett Foundation upon completion of applicant's fundraising efforts)

Description of Item (s)

Donor

Company *(if applicable)*

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone _____ Email _____

Signature