



Jett Foundation Ambassador Guide

Jett Foundation Mission Statement:

Jett Foundation empowers people and families impacted by Duchenne muscular dystrophy through the development of transformative programming, educational opportunities, and ongoing support for every stage of a Duchenne journey.



Table of Contents

Jett Foundation Office Information	2
What is a Jett Foundation Community Ambassador?	3
Jett Foundation's Role	4
The Ambassador Role	5
Guidelines for Communicating with Individuals and Parents/Caregivers	5
General Guidelines	5
Phone Calls	6
Emails	7
Ambassador Connection Follow-up	8
Social Media	8
Support Facebook Group Rules	8
Social Media Sites	10
Ambassador Agreement Link	11
Jett Foundation Resources	11



Jett Foundation Office Information

Website: <https://www.jettfoundation.org/>

Mailing Address: 65 Cordage Park Circle
Suite 130
Plymouth, MA 02360

Phone Number: 781-585-5566

Email address: info@jettfoundation.org

Ambassador Program Contact: Alexa Tinsley, Director of Programs

Email address: alexa@jettfoundation.org

Phone Number: 813-803-0585



What is a Jett Foundation Community Ambassador?

As an Ambassador for Jett Foundation, you are a local support liaison for Jett Foundation. You respond to inquiries made by individuals impacted by Duchenne and provide them with information regarding doctors and other resources. Offering a sympathetic ear for people seeking support and connecting them with the national Jett Foundation office is a major part of the position. Upholding Jett Foundation's mission is vital to your role. Our mission: Jett Foundation empowers people and families impacted by Duchenne muscular dystrophy through the development of transformative programming, educational opportunities, and ongoing support for every stage of a Duchenne journey.

Ambassadors must renew their commitment annually in order to remain a Jett Foundation representative. In order to become an Ambassador or renew your commitment, please go to this link:

https://jettfoundation.formstack.com/forms/ambassador_application_2024

Either the Ambassador or Jett Foundation may choose not to renew the relationship at either party's discretion.

There are four roles for Ambassadors: **Support Ambassador**, **Event Ambassador**, **Fundraising Ambassador** and **Special Project Ambassador**. You are welcome to serve in one or more of these four roles.

As a **Support Ambassador** for Jett Foundation, you are a support liaison for Jett Foundation. Based on your Agreement Form, Jett Foundation will connect you with individuals and families. You will provide them with information and resources that have been helpful to you in your journey and offer a sympathetic ear for people seeking support.



As an **Event Ambassador**, you are interested in hosting local events for those affected by Duchenne muscular dystrophy. The focus of this role would be to host activities that help provide support by bringing families together in a social setting. These events may be in person or virtual. An example of this would be hosting a local get together to raise awareness during our annual WDAD event.

As a **Fundraising Ambassador**, you would help assist with fundraising events in your community on behalf of Jett Foundation. You would also be a support for programs within Jett Foundation and assist families by providing ideas and support in fundraising. Based on your Agreement Form, Jett Foundation will connect you with individuals and families. You will provide them with information and resources that have been helpful to you in your journey.

As a **Special Project Ambassador**, you assist Jett Foundation in specific projects to further the mission of Jett Foundation. Examples might be helping edit the Jett Foundation website; offering input on Jett Foundation materials and programs from an individual/family perspective; reviewing our physicians' lists; or educating industry partners on individual/family perspectives and clinical trial experiences. A NDA is required for this type of Ambassador.

Jett Foundation's Role

Jett Foundation will forward family support requests received to Jett Ambassadors in the respected areas.

- Provide assistance for any inquiries and/or issues with which you are uncomfortable for any reason.
- For those running or hosting meetings/activities, Jett Foundation will promote the meetings through e-blasts, Jett Foundation Ambassador Facebook page and Jett Foundation website calendar (<https://www.jettfoundation.org/events/>).
- Provide materials for education and awareness promotions.
- Tracking connections provided to and received from ambassadors, along with providing connection information as it comes in.



The Ambassador Role

As a Community Ambassador, you will:

- Respond to support requests forwarded from the Director of Programs or Community Program Coordinator within 72 hours or notify us that you are not currently available.
- Participate in quarterly Ambassador meetings.
- Hold at least one meeting and/or activity within the year you are serving as Community Ambassador.
- Completion of special projects in a timely manner (if applicable).
- Maintain communication with the Jett Foundation office.
- Attend Jett Foundation webinars monthly
- Share Jett Foundation events and educational posts

Guidelines for Communicating with Individuals and Parents/Caregivers

General Guidelines

- Whenever possible, respond to emails and phone calls within three days.
- If you are temporarily unable to respond to phone calls or emails for any reason, let the Jett Foundation staff know. We can refer calls from your area to another ambassador until you are available.
- Keep a list of local and state resources (including funding resources, physicians and state agencies) that may be helpful to others in your area so that you can refer individuals or parents for help. Please refer to the Jett Foundation Website at www.jettfoundation.org for resources already provided to families, including state-specific resource guides.
- A list of Jett Foundation website and social media resources can be found at the end of this document.
- Be sure to direct families to the Jett Foundation website event calendar. This is a great opportunity to help them get the information they may need - <https://www.jettfoundation.org/events/>.



-
- Avoid recommending specific therapies or treatments, even ones that have worked well for you or your family member. Remember that experiences can vary widely from person to person. What works for one family/individual might be harmful to another. If you feel compelled to share such information, please note that it is your personal experience and not an official recommendation and/or endorsement from Jett Foundation.
 - Any information that an individual, family, or contact has shared with you should be treated as confidential and should only be shared with Jett Foundation and the Director of Programs. Do not share with others unless you have received permission to do so.
 - All communication should be professional in nature. Do not use pet names or terms of endearment (like sweetie or honey) while acting as a representative of Jett Foundation.
 - As an Ambassador, you are not required to meet with families in your area, but you can do so if you choose. However, if you do meet with another family member, make sure that you do so safely! Meet in a public place and bring along a friend.
 - You may not get a response from a connection. Please don't let that discourage you! Keep trying and know that sometimes people will reach out in the future. Check to ensure you are using the correct email address. Follow-up with them on the same schedule as other connections.

Phone Calls

During a typical phone call, you may be asked a lot of questions about Duchenne muscular dystrophy. If you do not know the answers to any questions, do not feel intimidated. Share what you know, and refer callers to Jett Foundation with any questions you cannot answer. Remember the following tips during phone calls:

- Make sure to get all contact information (mailing address, phone number and email address) so that you can keep in touch with the person (as needed) and also to pass on to Jett Foundation.
- If a caller makes you feel uncomfortable, you do not know the answer to a question, or if you feel like the caller needs more support than you can provide, get their phone number and have Jett Foundation staff get back to them.



Emails

When Jett Foundation receives an inquiry from an individual/family, Jett Foundation staff will respond by email or phone. Jett Foundation staff will provide general information about Jett Foundation and Duchenne muscular dystrophy. We will include your name, email address or phone number, depending on your preferences. You will then be connected to them directly through a separate email.

We ask that you consider the following points when corresponding to people who come to you through Jett Foundation:

- A standard email signature will let people know exactly who you are when you send emails on behalf of Jett Foundation. A good signature will include your name and your Jett Foundation affiliation (“Jett Foundation Support Ambassador for [name of your area]”). You may also include information about the individual in your family who is affected by DMD in your signature. Do not include information on other affiliations (your job, other organizations you are a part of, etc.) in your email signature when you are communicating with someone on behalf of Jett Foundation. Representing yourself as a Jett Foundation ambassador and as an employee or member of another group may create the mistaken impression that there is an affiliation between Jett Foundation and the other group or business. Information on how to change and manage multiple signatures in gmail can be found [here](#). If you need help setting this up, please feel free to reach out to Alexa, Director of Programs, at alexa@jettfoundation.org.
- If someone asks questions about Duchenne, a good way to answer is to refer them to an appropriate area of Jett Foundation’s website. Our [educational Welcome Packet](#) can be especially helpful to newly diagnosed families and parents. Including links to these documents in your emails is a helpful way to provide information to new contacts.
- If you are not sure how to respond to an email, forward it to Alexa Tinsley, Director of Programs, at alexa@jettfoundation.org. Please keep in mind that you are representing Jett Foundation when you respond to the emails that we send to you. We trust you will present a positive view of Jett Foundation. Jett Foundation is always looking to provide the best services we can to our families. If you have questions or concerns about any of our policies, actions or activities, please contact us so we may address those questions and meet your needs.



Any contact information that you obtain as a Jett Foundation Ambassador cannot be used for any purpose other than Jett Foundation activities and support. A Jett Foundation mailing list must not be used to solicit funds for a non-Jett Foundation fundraiser or to recruit new families to a different organization.

Ambassador Connection Follow-up

- You will receive connections from the Director of Programs as they are made.
- Reach out and touch base with these families, even if it is just to say hello. Knowing that you are there over time can mean so much to these families.
- This is also a great time to update people about new Jett Foundation programs and services.

Social Media

Social media is a powerful way for organizations to reach out to their supporters and to provide support and information. Jett Foundation has an official Facebook Group for individuals and families impacted by Duchenne to connect with one another and a Facebook Page through which people can get news from Jett Foundation. We also have Instagram, LinkedIn, Twitter, and YouTube accounts (links provided on page 10). Please review our Facebook Group rules below.

Support Facebook Group Rules

The goal of this Facebook Group is to connect individuals, families and friends who are impacted by Duchenne and to provide them with an opportunity to network with one another and with friends, families and supporters. We will occasionally post about Jett Foundation hosted fundraising events, but will not post fundraisers for other non-profit groups or GoFundMe links.



VERY IMPORTANT - Personal attacks are not permitted; and anyone who sends one is automatically moderated or could be removed from the group, depending upon the severity of the post. We want this to be a positive zone for our individuals and families. Please refrain from criticizing physicians or other medical professionals by name. Remember that the doctor that was not a “good fit” for you may have saved someone else’s life. Constructive input is welcome, but destructive/negative comments that may affect Jett Foundation’s mission moving forward are not and could be grounds for removal of the group member. Additionally, profanity is not allowed.

Privacy Disclaimer: We do our best to protect the privacy of our families; however, it is the responsibility of each user to determine what he/she shares on the internet. On Facebook, each user may set his/her individual privacy preferences while each group determines their privacy settings by choosing whether it is an open, closed or secret group. The Fighting Duchenne Facebook Group is currently a private group, which allows others to see that the group exists but blocks non-members from reading posts within the group. The administrators of the group must decide to accept or deny requests based on a limited amount of information, so please post responsibly. Before posting in a group, please ask yourself, “Am I comfortable with sharing that information with people I do not know?” You may also find Consumer Reports’ “Protect your privacy on Facebook” helpful:

<https://www.consumerreports.org/privacy/facebook-privacy-settings/>

PLEASE NOTE: If you need something from Jett Foundation, contact Alexa Tinsley, Director of Programs at alexa@jettfoundation.org or 813.803.0585.

*The inclusion of links does not imply endorsement by Jett Foundation, unless stated otherwise. Jett Foundation makes no endorsement, expressed or implied, of any links to or from this group, nor is it responsible for the content or activities of any linked sites or comments/posts made by members of the group. Any questions or concerns should be directed to the administrator(s) of the group.

**Announcements of seminars, publications and other publicly available resources specifically designed to provide direction for individuals and families in the care for their child and/or the individual may be posted. Please refrain from posting any sales items and/or advertisements for products and/or services.



Ambassadors are asked to remember the following guidelines when posting on any Jett Foundation or DMD-related social media forum, even if the forum is not operated by Jett Foundation:

- Do not offer medical advice or treatment suggestions. It is okay to say things like, “My child showed some improvement when using CoQ10,” but keep in mind that all individual cases can be very different and what works for one individual may not work for another. If another post on a forum asks for treatment recommendations, suggest that they see a known DMD clinician. If you do not know of one in their area, refer them to Jett Foundation, and we will be glad to give them information.
- If you see something on the page that makes you uncomfortable, please reach out to Jett Foundation. Jett Foundation staff do their best to moderate each group, but we need your help to keep an eye on things.
- Avoid personal attacks. Disagreements should be kept private and not posted on a public forum. Do not publicly insult other individuals, parents, doctors, or organizations on any social media site or public forum. If you have a problem or issue that needs to be addressed by Jett Foundation, contact Alexa Tinsley at alexa@jettfoundation.org or 813.803.0585.

Social Media Sites

The following social media sites have been established by Jett Foundation:

YouTube: <https://www.youtube.com/@jettfoundation>

Facebook Page: <https://www.facebook.com/jettfoundation>

Facebook Group: <https://www.facebook.com/groups/525031991724809>

Twitter: <https://twitter.com/JettFoundation>

Instagram: <https://twitter.com/JettFoundation>

LinkedIn: <https://www.linkedin.com/company/jettfoundation/>

Jett Foundation’s Podcast: <https://jettfoundation.podbean.com/>



Ambassador Agreement Link

You are required to fill out an Ambassador Agreement yearly. Click [HERE](#) for the 2024 Ambassador Application. If for any reason you are unable to fulfill your duties as an Ambassador, you must alert Jett Foundation staff immediately.

Jett Foundation Resources

Website: <https://www.jettfoundation.org/>

Family Support Groups: <https://www.jettfoundation.org/family-support-groups/>

Event Calendar: <https://www.jettfoundation.org/events/>

Jett Giving Fund: <https://www.jettfoundation.org/giving-fund/>

Community Webinars: <https://www.jettfoundation.org/community-webinars/>

Camp Promise: <https://www.jettfoundation.org/camp-promise/>

Educational Welcome Packet: <https://www.jettfoundation.org/about-duchenne/diagnosis/>

About Duchenne: <https://www.jettfoundation.org/about-duchenne/>

Clinical Trials: <https://www.jettfoundation.org/about-duchenne/clinical-trials/>

Jett Blogs: <https://www.jettfoundation.org/blog/>