Parent Project Muscular Dystrophy Corporate Relations Policy

Parent Project Muscular Dystrophy’s (PPMD) mission is to end Duchenne. We accelerate research, raise our voices in Washington, demand optimal care for all people living with Duchenne, and educate the global community. PPMD executes our mission through five key objectives: Research, Advocacy, Care, Community, and Education.

PPMD recognizes that partnership and engagement with various entities can serve our mission and that patients and their families benefit through improved endeavors and services that help meet their needs and advance the state of care. As such, PPMD will develop a variety of strategic relationships with corporate sponsors and work closely with them to achieve our mission through relevant projects, efforts, initiatives, programs, and more. Most relationships will have educational or engagement objectives; others may be intended to create awareness or promote research; and some may be multifaceted in nature. Every single partnership is entered into for the purpose of ultimately recognizing our shared goal: to end Duchenne and benefit the Duchenne community.

PPMD’s corporate relations policy is intended to ensure that the corporate relationships entered into by PPMD are conducted in a manner consistent with our mission, objectives, and core values. This ensures that PPMD will never compromise its independence or engage in a corporate relationship that will affect the organization’s credibility or integrity.

Corporate relationships entered into by PPMD follow the basic requirements set forth below:

1. **Mission Benefit**
   Corporate relationships provide a meaningful and substantial mission-related benefit to the Duchenne community through projects, efforts, initiative, programs, or the execution of PPMD’s mission.

2. **Independence**
   While PPMD may accept financial support from corporations, PPMD always exercises independent judgment in all its decision-making. PPMD retains sole discretion for the content, quality, and scientific and educational integrity of all sponsored programs, events, and publications. PPMD shall avoid any potential conflicts of interest when establishing and maintaining corporate relationships. As such, if a PPMD board member participates on a corporate patient advisory board, committee or any other formal entity organized by a corporate partner, that board member will recuse themselves from any discussion around that partner.

3. **Communications**
   PPMD is transparent about and publically communicates its policies regarding relationships with corporate sponsors. PPMD materials directed to the public
contain accurate terms or statements such that reasonable individuals will understand the nature and extent of the corporate relationship.

4. **Endorsement**
PPMD does not endorse any product for financial gain and/or does not endorse particular products, types of products, studies, trials, therapies, or potential therapies. Special scrutiny, including regulatory guidelines, are applied when prescription and over-the-counter drugs and devices are involved to avoid unintended endorsement, suggestion of product superiority, or bias for or against a specific product.

5. **Privacy**
PPMD protects the privacy of participants in corporate-sponsored activities and/or programs and does not share mailing or contact lists of any type; furthermore, all of the information contained in PPMD’s patient registry, DuchenneConnect, is maintained in a secure database. Any information that could identify individuals or their family members will not be shared without approval from the individual registrant. Only the DuchenneConnect team and the technical team have access to registrants’ identified information.

6. **Disclosure**
PPMD will disclose financial support received as a result of a corporate relationship vis-à-vis public announcements and on its website on an ongoing basis with a comprehensive update on an annual basis within six months of the close of the fiscal year.

7. **Exclusivity**
In general, there are no exclusive arrangements in partnerships, projects, efforts, initiative, programs, or the execution of PPMD’s mission. PPMD resolutely believes it is our role to move the Duchenne field forward and exclusive partnership could prohibit the success of this. PPMD treats all corporate sponsors fairly and honestly.

8. **Adherence**
The corporate partner and relationship will adhere to all applicable state, federal, and local rules and regulations.

9. **Advance Review and Approval**
Any use of any kind of the PPMD name, logo, and/or identifying marks in a corporate relationship must be reviewed and approved by PPMD in writing in advance of use, including in statements or any other materials from the corporation.

10. **Written Agreement**
PPMD determines appropriate areas for corporate sponsorship, types of sponsorship, and length or duration of sponsorship, and has a written agreement or scope of work outline between itself and the corporation prior to implementation of the corporate relationship. The agreement will clearly
indicate: (i) the amount of money that will be transferred to PPMD; (ii) a written description of the mission-driven activity supported that both parties will agree to use for purposes of disclosure to the general public; (iii) a general timeline of the effort; (iv) whether the consideration is unrestricted or restricted to support a particular event or program activity; (v) the role of a corporate steering committee, if one exists; (vi) PPMD retains complete control of and right of approval over all content related to the event or program activity; and (vii) whether, and if so, how the organization’s name, logo, and/or any identifying marks will be used by a corporation.

11. Annual Evaluation
   The PPMD Board of Directors will, on an annual basis, evaluate the total amount of corporate support received as a percentage of total revenue.