

Leveraging Workplace Giving Campaigns to End Duchenne

**A guide for raising money through the
United Way, Combined Federal Campaign (CFC),
& State Employee Campaigns**



**Parent Project
Muscular Dystrophy**

LEADING THE FIGHT TO END DUCHENNE

Dear PPMD family, friend, and supporter:

The purpose of this document is to help parents and friends of boys with Duchenne muscular dystrophy (Duchenne), to better leverage the established framework of the United Way, the Federal Workers Combined Federal Campaign (CFC), and other charity campaigns to raise funds in support of ending Duchenne. Developing a better understanding of each type of fundraising campaign will hopefully enhance and accelerate overall fundraising efforts.

Unfortunately, our son Michael was diagnosed with Duchenne in June 2010. Our family started our fundraising efforts in support of Parent Project Muscular Dystrophy (PPMD) almost immediately in effort to help save Michael and the other boys. Having collectively worked for the government (Navy) and several large corporations, we were hopeful we could leverage the existing, annual charity organizations already in place. The processes of working with each charity framework turned out to be a little more complicated than we had expected. To help other friends and parents in their fundraising efforts, we would like to share what we have learned.

We hope this document serves you, and boys, well!

Sincerely,

Bill & Kathy Brown
PPMD Supporters



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United Way



WORKPLACE GIVING

United Way is a worldwide network in 45 countries and territories, including nearly 1,300 local organizations in the U.S. It advances the common good, creating opportunities for a better life for all, by focusing on the three key building blocks of education, income, and health. The United Way movement creates long lasting community change, by addressing the underlying causes of problems that prevent progress in these areas. Live United is a call to action for everyone to become a part of the change.

In our experience, many companies have an annual United Way fundraising effort each fall. Employees are encouraged to support the community by donating to general or particular causes. The United Way offers a way to donate that is convenient to both the companies and the employees. The companies are able to present a well-formed and well-thought out set of charity options to their employees. The employees are provided a straight-forward set of charity choices and an automatic payment process. Additionally, the employee donations are conveniently and automatically deducted from their paychecks and their donation is subsequently reflected on their annual W-2 earning statements. The employee can then deduct the donation when they file their income taxes.

We wanted to share our United Way experiences, so you too can hopefully leverage the United Way in support of PPMD, Duchenne research, and all the boys.

OVERHEAD COSTS

Donations to PPMD through any United Way are reduced by an approximate range of 14%–18% to understandably help cover United Way's overhead costs.

If parents, relatives, or friends are going to make donations, they may want to consider donating directly to PPMD via check, or participating in PPMD's monthly giving program, STIR (Striving To Impact Research) to ensure the full amount is realized by PPMD:
ParentProjectMD.org/STIR

Charity Models

We have not yet found any official United Way terminology for their charity models.

However, while working with a couple of different United Way staff members, the concepts of "Open" and "Closed" United Way charity models were discussed.

Open United Ways

Open United Ways will collect and send donations to any/all 501(c)3 charity organizations such as PPMD. 501(c)3 charities have their own Employer Identification Number (EIN) as assigned by the IRS.

Closed United Ways

Closed United Ways will only collect funds for causes they explicitly choose. If you are unable to find Parent Project Muscular Dystrophy in your local United Way or Corporate donations directory, ask your United Way Coordinator to verify whether or not they support PPMD. If you have confirmed they do not support PPMD, we have outlined several approaches below to ask a Closed United Way to either add PPMD to their explicit list of charities, or alternatively to collect and then route funds to PPMD through another Open United Way to PPMD.

Individual Donors

How to fund PPMD via a pledge to an
“Open” or “Closed” United Way

Pledge to an “Open” United Way

Your United Way supports any Charitable 501(c)3 organization – sometimes called an Open United Way. Open United Ways will collect and send donations to any 501(c)3 charity.

Donors should specify the following on your Open United Way donation form, so they can route your funds to PPMD:

Parent Project Muscular Dystrophy*
Hackensack, NJ 07601
EIN (Employer Identification Number): 31-1405490
Phone: 201-250-8440

**If you are trying to locate PPMD in some type of charity look-up guide, PPMD may also be listed as: The Parent Project for Muscular Dystrophy Research INC. You may also see the cities of Fort Lee, NJ 07024 or Middletown, OH 45042.*

Charity Codes

Sometimes large companies do not use the EIN. Rather, they provide an online guide for employees to search to locate a particular charity and donation code.

PPMD’s Address

Parent Project Muscular Dystrophy
401 Hackensack Avenue, 9th Floor
Hackensack, NJ 07601
t. 201-250-8440 f. 201-250-8435
e. info@parentprojectmd.org
ParentProjectMD.org

OVERHEAD COSTS

Contributing directly (outside the United Way) ensures your full donation goes to PPMD, since it avoids the 14%–18% reduction collected by the United Way to cover their expenses.

Pledge to a “Closed” United Way

Your United Way supports only pre-selected causes – sometimes called a Closed United Way.

A Closed United Way will only allow donations for causes they explicitly choose. If you are unable to find Parent Project Muscular Dystrophy in your local United Way or corporate donations directory, ask your United Way Coordinator to verify whether or not they support PPMD.

If they do not support PPMD, you will not be able to provide funds to PPMD via your United Way, unless your United Way team works to make other arrangements – see the “Parent/United Way Coordinator” section of the guide for several options to gain support through a Closed United Way.

If United Way arrangements cannot be made via your United Way (or another family member), please make a direct, tax free donation to PPMD.

To donate directly to PPMD, go to ParentProjectMD.org and click on the ‘Donate Now’ button. There is a STIR (Striving To Impact Research) option if you wish to give monthly in an automatic fashion – similar to the United Way. You will receive receipts from PPMD so you can claim the donation(s) on your taxes.

Parent/United Way Coordinator

How to arrange local United Way Support for PPMD

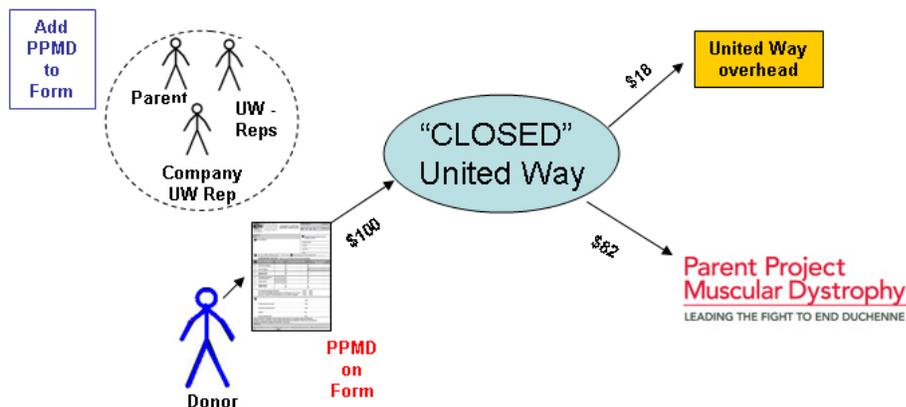
Unfortunately, my employer operated with a Closed (but helpful and dedicated) United Way. It initially appeared there was no path forward to have all my friends and coworkers leverage the annual United Way fundraising campaign to support PPMD and our son Michael. However, working with Human Resources, Payroll, our Closed United Way, and another nearby Open United Way, we were able to get PPMD supported.

Here are some options to get PPMD funded through a Closed United Way campaign.

Option 1: Add PPMD to the list of charities supported by the local United Way

Ask the local, Closed United Way to explicitly choose PPMD as a supported charity. Work with your local United Way and your company's United Way Representative to determine what documentation is required, and their level of willingness. Closed United Ways are not always open to accepting new charities. If they are willing, then contact PPMD at 201-250-8440 and ask them to support your efforts to get PPMD on the supported list of charities.

The following diagram outlines the flow and division of money using the example of a \$100 per month donation. Understandably, the United Way will allocate a portion of each donation to cover their overhead. The overhead is represented as the 18% / \$18 in the yellow box.



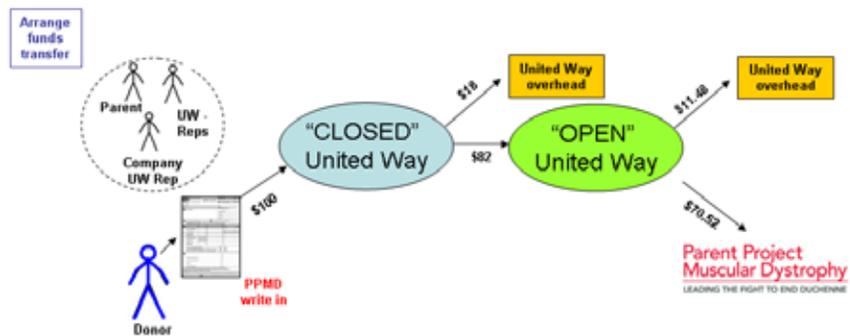
Option 2: Employee donates to a Closed United Way, which is then routed to an Open United Way, then to PPMD

This approach requires two cooperating United Ways. Essentially, the Closed United Way is willing to let the donors/employees earmark funds to PPMD by 'writing in' PPMD on their donation forms. The Closed United Way will gather the earmarked funds, then transfer them to another Open United Way, which subsequently routes the funds to PPMD.

Unfortunately, but certainly understandably, every United Way which processes the funds in any manner will subtract a percentage of the funds to cover their overhead. I have seen overhead costs range between 14% and 18% per United Way. So, if your local Closed United Way collects the funds and charges 14% and hands it to an Open United Way which charges another 18%, you could end up with almost one third of the funds going to support United Way overhead. Remember, all support goes to the United Way and PPMD – both great causes.

You will need to work closely with the local Closed United Way to find another Open United Way willing to provide both the funding assurances and the financial arrangements.

The following diagram outlines the flow and division of money using the example of a \$100 per month donation. Each United Way will allocate a portion of each donation passing through their organization to cover their respective overhead. The overhead is represented as the 18% / \$18 for the Closed United Way, and another 14% / \$11.48 for the second Open United Way in the yellow boxes.



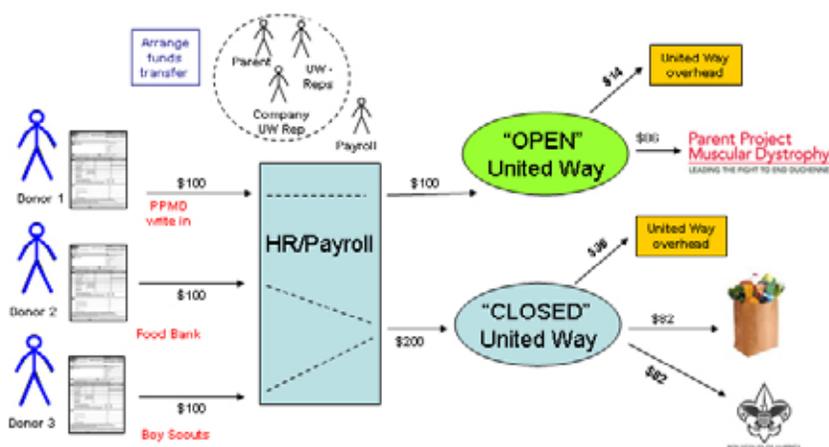
Option 3: Employee donates on Closed United Way form to Company HR/Payroll Department. Funds are then transferred by the Company HR/Payroll, to another Open United Way, to PPMD

In this option, donations earmarked for PPMD are routed from HR/Payroll directly to an Open United Way. Non-earmarked funds are routed to the incumbent, Closed United Way.

This approach is a little more complex, and requires two co-operating United Ways, as well as the support of a company's HR/Payroll department. The Closed United Way allows the company to leverage their local donation forms to earmark funds for PPMD by asking donors to write in "PPMD" at the Write-in/Other spot on the form.

The company's HR/Payroll department agrees to separate the PPMD earmarked forms and collect the funds from the employees. HR/Payroll department then sends the funds to a trusted, Open United Way, who then routes the funds to PPMD. Since only one United Way actually processes the funds, there is only one United Way overhead charge. Seems complicated, but it works – especially when 1) everyone is out of the mindset of appreciating the donor's wishes, and 2) everyone realizes the PPMD boys need help too. This Option 3 solution is what I arranged with my employer.

The following diagram shows that the \$100 monthly PPMD earmarked funds are routed by HR/Payroll to an Open United Way.



Combined Federal Campaign (CFC)



FOR U.S. FEDERAL WORKERS

If your friends, family, or relatives work for the Federal Government, they can support PPMD through the Combined Federal Campaign (CFC), which runs from September 1st – December 15th. Please look for “Parent Project Muscular Dystrophy.” The 5-digit 2012 designation code for PPMD is 10749 and the EIN is 31-1405490.

According to the CFC website (OPM.gov/CFC), as of June 2012, “CFC is the world’s largest and most successful annual workplace charity campaign, with more than 300 CFC campaigns throughout the country and internationally to help to raise millions of dollars each year. Pledges made by Federal civilian, postal and military donors during the campaign season (September 1st to December 15th) support eligible non-profit organizations that provide health and human service benefits throughout the world. The Director of OPM has designated to the Office of CFC Operations responsibility for day-to-day management of the CFC.”

More info: OPM.gov/CFC

State Employee Campaigns



FOR STATE EMPLOYEES

Many states offer employee campaigns. To date, we have only researched the State of Kentucky, where we reside. Please consider researching similar arrangements for your state.

State of Kentucky employees can support PPMD through the Kentucky Employees Charitable Campaign (KECC). In step 2 of the form, write in:

Parent Project Muscular Dystrophy
401 Hackensack Avenue, 9th Floor, Hackensack, NJ 07601
t. 201-944-9985 • 800-714-5437
f. 201-944-9987 e. info@parentprojectmd.org

According to KECC.org, as of October 2010, "The [KECC] is a partnership of Kentucky state employees and six accredited state-wide charities, who together work to make a significant difference in the lives of our families, friends, and neighbors throughout the Commonwealth. KECC partner charities represent more than a thousand charitable programs and agencies addressing health and human services needs in Kentucky. Since 1993, the KECC has provided the opportunity for state employees to contribute to eligible charitable organizations through the state's payroll deduction process. This is your campaign, created and run by state employees, and in 2009, you surpassed 2008 and raised more than \$1,415,000 to help build a better Kentucky! Thanks for you hard work and generosity!"

More KECC info: KECC.org