



Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

Gift Acceptance Policy

Revised August 2, 2017

The mission of the National Foundation for Ectodermal Dysplasias (NFED) is to empower and connect people touched by ectodermal dysplasias through education, support and research. We offer numerous programs to help the community better understand ectodermal dysplasias and to provide the support and assistance affected individuals and your families need to live empowered and successful lives. We are the only ectodermal dysplasias advocacy group in the United States.

The NFED received financial support from a diverse group of resources in 2016, including:

- Individuals including the many family fundraiser participants, care providers, and friends of the NFED.
- Corporations including gifts of \$5,000 and up from Straumann - \$35,773, Broadridge Securities Processing Solution - \$10,000, Oracle America, Inc. - \$10,000, FRAC Fuel Solutions, Inc. - \$7,500, and the many other community businesses who have sponsored family fundraisers.

Of this total, the NFED received 5.18% of funding from pharmaceutical, biotechnology and medical device companies which includes Straumann USA - \$35,773 (previously listed), Straumann Corporation - \$4,220, Gene Dx, Inc. - BIORreference Laboratories - \$2,500, Medtronic Foundation - \$500, the GE Foundation - \$440, and the Pfizer Foundation Matching Gifts Program - \$150.

- Immediate and extended families of affected individuals who know the benefit of NFED programming.
- Organizations such as Joliet Woman's Club, Delta Theta Tau, Kiwanis Clubs and many other community groups who care about our mission.
- Foundations like the Louis J. and June E. Kay Foundation, Hubbard Broadcasting Foundation, and Blanche March Foundation who support 501c3 nonprofits which includes the NFED.

All donor information will remain confidential within the NFED office with the exception of information required by the state and/or federal government.

The names and addresses of donors making memorial or honorarium gifts or contributing to third party fundraisers will have their names and addresses shared so that appropriate acknowledgements may be provided unless the donor indicates otherwise. At no time will the amount of individual gifts be shared.

Gifts from donors will be properly acknowledged in a timely manner and receipts will be issued when requested or required by law. All designated gifts will be solely used for the purpose intended by the donor. Receipts for donated goods will include a good-faith estimate of the fair market value.

The NFED reserves the right to refuse gifts that would compromise its ethics, mission or other interests. The NFED will not sell or share a listing of its donors or compromise donor contact information in any other way.

The NFED will not compensate, whether through commissions, finders' fees, or other means, any third party for directing a gift or a donor to the NFED.

A record will be kept of individuals indicating plans to remember the NFED in their estate planning. The NFED is grateful for any such gifts. However, as needed, a special committee from the Board of Directors will determine, on a case by case basis, whether a specific non-cash gift will be accepted.

The NFED accepts pledges for future funding. It is important that donors indicate the amount of the pledge, the frequency of the pledge (if applicable) and the duration of the pledge. Pledges of more than \$500 per month will be booked as a receivable while all pledges under that amount will be deposited as directed until the pledge has been fulfilled. Booked pledges will continue to be accounted for until the pledge is completed.

Third party fundraising events are often held to benefit the NFED. The NFED prefers the donor to directly contribute in the name of the NFED to maximize the tax deduction allowed, and minimize any claims of improper expenses. An estimate of event expenses which the NFED shall reimburse should be preapproved, to ensure the NFED does not incur any unplanned liabilities. In order to minimize the administrative burden placed on the NFED staff for small events, the minimum threshold for the NFED staff to be responsible for disbursing expenses shall be \$5,000 (similar to the threshold when NFED staff will travel to an event), with any exceptions requiring Executive Director prior approval.

Corporate Donations and Foundation Grants

The NFED will adhere to all restrictions and reporting requirements associated with gifts of this nature. The NFED will not grant exclusivity or endorsement for any product associated with a corporate gift.

Types of Gifts the NFED Accepts:

- Cash equivalents (checks). These gifts include gifts of cash, checks and pledges. Checks should be made out to: National Foundation for Ectodermal

Dysplasias or NFED. (Gifts of cash are discouraged as cancelled checks are important documents for IRS purposes for the donor.)

- Pledges are welcome and are described below.
- Gifts of securities (stocks and bonds). Marketable securities of all types are accepted and may be a useful gift option for donors. The NFED's Investment Committee will determine the appropriate time to sell although most will likely be sold as soon as is practical. Normally, the only securities accepted will be those of companies (or mutual funds) that are widely, publicly traded.
- Gifts of real estate. The Foundation will accept gifts of real estate on a case-by-case basis with the NFED's Investment Committee responsible for appropriate disposal with consult by a certified appraiser.
- Personal Property (e.g. automobiles, jewels). Personal property will only be accepted on a case by case basis with the Investment Committee charged with disposing of any accepted gifts in this category with consult by a certified appraiser.
- Art works. Works of art are difficult to market but may be accepted on a case by case basis with the Investment Committee charged with the disposal of any accepted gifts in this category with consult by a certified appraiser. Gifts of art work for use by the NFED in its building should be discussed with the Executive Director. Gifts of art for auction events are acceptable.
- Planned Gifts. These gifts, which include such instruments as bequests, life insurance, retirement plan distributions, Charitable Remainder Trusts and Charitable Lead Trusts are almost always welcomed from donors interested in making such gifts. While it is helpful to discuss these gifts with the NFED in advance, it is not necessary to do so. However, donors should always discuss such gifts with their professional advisors. At this time the NFED does not have a "pooled income fund," nor does it offer gift annuities. Endowment funds are accepted on a case by case basis contingent on the fund value and interest paid to the NFED.
- In-kind gifts of services. These are accepted and welcomed by the NFED after discussion with the NFED Executive Director. Because of the nature of the organization, not all offers for services can be accepted.
- In-kind gifts of materials (office furniture, technology, etc.). Gifts of in-kind materials are welcome only after discussion with the NFED Executive Director and, as appropriate, further approval by the Executive Committee.

Corporate Relations Policy

The NFED will post disclosures on the website within 6 months of the NFED's fiscal year (by June 30). The NFED will ensure disclosure information is easily accessible from the homepage. As stated under the Gift Acceptance Policy, the NFED received 5.18% of funding in 2016 from pharmaceutical, biotechnology and medical device companies which includes Straumann USA - \$35,773 (previously listed), Straumann Corporation - \$4,220, Gene Dx, Inc. - BIOReference Laboratories - \$2,500, Medtronic Foundation - \$500, the GE Foundation - \$440, and the Pfizer Foundation Matching Gifts Program - \$150.

