

INTERNAL REVENUE SERVICE
P. O. BOX 2508
CINCINNATI, OH 45201

DEPARTMENT OF THE TREASURY

Date: JUL 28 2006

COFFIN-LOWRY SYNDROME FOUNDATION
C/O MARY HOFFMAN
3045 255TH AVE SE
SAMMAMISH, WA 98075

Employer Identification Number:
20-3377465
DLN:
606200154
Contact Person:
MRS. C. SMITH ID# 52445
Contact Telephone Number:
(877) 829-5500
Accounting Period Ending:
December 31
Public Charity Status:
170(b)91) (A) (vi)
Form 990 Required:
Yes
Effective Date of Exemption:
August 9, 2005
Contribution Deductibility:
Yes
Advance Ruling Ending Date:
December 31, 2009

Dear Applicant:

We are pleased to inform you that upon review of your application for tax exempt status we have determined that you are exempt from Federal income tax under section 501(c)(3) of the Internal Revenue Code. Contributions to you are deductible under section 170 of the Code. You are also qualified to receive tax deductible bequests, devises, transfers or gifts under section 2055, 2106 or 2522 of the Code. Because this letter could help resolve any questions regarding your exempt status, you should keep it in your permanent records.

Organizations exempt under section 501(c)(3) of the Code are further classified as either public charities or private foundations. During your advance ruling period, you will be treated as a public charity. Your advance ruling period begins with the effective date of your exemption and ends with advance ruling ending date shown in the heading of the letter.

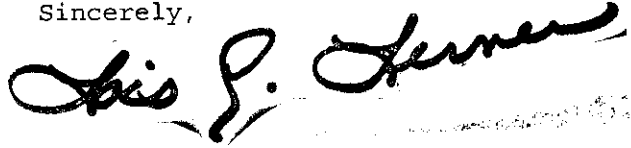
Shortly before the end of your advance ruling period, we will send you Form 8734, Support Schedule for Advance Ruling Period. You will have 90 days after the end of your advance ruling period to return the completed form. We will then notify you, in writing, about your public charity status.

Please see enclosed Information for Exempt Organizations Under Section 501(c)(3) for some helpful information about your responsibilities as an exempt organization.

Letter 1045 (DO/CG)

COFFIN-LOWRY SYNDROME FOUNDATION

Sincerely,

A handwritten signature in black ink, appearing to read "Lois G. Lerner". The signature is written in a cursive style with a large initial "L".

Lois G. Lerner
Director, Exempt Organizations
Rulings and Agreements

Enclosures: Information for Organizations Exempt Under Section 501(c)(3)
Statute Extension

COFFIN-LOWRY SYNDROME FOUNDATION

INFORMATION FOR ORGANIZATIONS EXEMPT UNDER SECTION 501(c)(3)

WHERE TO GET FORMS AND HELP

Forms and instructions may be obtained by calling toll free 1-800-829-3676, through the Internet Web Site at www.irs.gov, and also at local tax assistance centers.

Additional information about any topic discussed below may be obtained through our customer service function by calling toll free 1-877-829-5500.

NOTIFY US ON THESE MATTERS

If you change your name, address, purposes, operations or sources of financial support, please inform our TE/GE EO Determinations Office at the following address: Internal Revenue Service, P.O. Box 2508, Cincinnati, Ohio 45201. If you amend your organizational document or by-laws, or dissolve, provide the EO Determinations Office with a copy of the amended documents. Please use your employer identification number on all returns you file and in all correspondence with the Internal Revenue Service.

FILING REQUIREMENTS

In your exemption letter we indicated whether you must file Form 990, Return of Organization Exempt From Income Tax. Form 990 (or Form 990-EZ) is filed with the Ogden Submission Processing Center, Ogden UT 84201-0027.

You are required to file a Form 990 only if your gross receipts are normally more than \$25,000.

If your gross receipts are normally between \$25,000 and \$100,000, and your total assets are less than \$250,000, you may file Form 990-EZ. If your gross receipts are over \$100,000, or your total assets are over \$250,000, you must file the complete Form 990. The Form 990 instructions show how to compute your "normal" receipts.

Form 990 Schedule A is required for both Form 990 and Form 990-EZ.

If a return is required, it must be filed by the 15th day of the fifth month after the end of your annual accounting period. There are penalties for failing to timely file a complete return. For additional information on penalties, see Form 990 instructions or call our toll free number.

If your receipts are below \$25,000, and we send you a Form 990 Package, follow the instructions in the package on how to complete the limited return to advise us that you are not required to file.

If your exemption letter states that you are not required to file Form 990, you are exempt from these requirements.

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UNRELATED BUSINESS INCOME TAX RETURN

If you receive more than \$1,000 annually in gross receipts from a regular trade or business you may be subject to Unrelated Business Income Tax and required to file Form 990-T, Exempt Organization Business Income Tax Return. There are several exceptions to this tax.

1. Income you receive from the performance of your exempt activity is not unrelated business income.
2. Income from fundraisers conducted by volunteer workers, or where donated merchandise is sold, is not unrelated business income.
3. Income from routine investments such as certificates of deposit, savings accounts, or stock dividends is usually not unrelated business income.

There are special rules for income derived from real estate or other investments purchased with borrowed funds. This income is called "debt financed" income. For additional information regarding unrelated business income tax see Publication 598, Tax on Unrelated Business Income of Exempt Organizations, or call our toll free number shown above.

PUBLIC INSPECTION OF APPLICATION AND INFORMATION RETURN

You are required to make your annual information return, Form 990 or Form 990-EZ, available for public inspection for three years after the later of the due date of the return, or the date the return is filed. You are also required to make available for public inspection your exemption application, any supporting documents, and your exemption letter. Copies of these documents are also required to be provided to any individual upon written or in person request without charge other than reasonable fees for copying and postage. You may fulfill this requirement by placing these documents on the Internet. Penalties may be imposed for failure to comply with these requirements. Additional information is available in Publication 557, Tax-Exempt Status for Your Organization, or you may call our toll free number shown above.

FUNDRAISING

Contributions to you are deductible only to the extent that they are gifts and no consideration is received in return. Depending on the circumstances, ticket purchases and similar payments in conjunction with fundraising events may not qualify as fully deductible contributions.

CONTRIBUTIONS OF \$250 OR MORE

Donors must have written substantiation from the charity for any charitable contribution of \$250 or more. Although it is the donor's responsibility to obtain written substantiation from the charity, you can assist donors by providing a written statement listing any cash contribution or describing any

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donated property.

This written statement must be provided at the time of the contribution. There is no prescribed format for the written statement. Letters, postcards and electronic (e-mail) or computer-generated forms are acceptable.

The donor is responsible for the valuation of donated property. However, your written statement must provide a sufficient description to support the donor's contribution. For additional information regarding donor substantiation, see Publication 1771, Charitable Contributions - Substantiation and Disclosure Requirements. For information about the valuation of donated property, see Publication 561, Determining the Value of Donated Property.

CONTRIBUTIONS OF MORE THAN \$75 AND
CHARITY PROVIDES GOODS OR SERVICES

You must provide a written disclosure statement to donors who receive goods or services from you in exchange for contributions in excess of \$75.

Contribution deductions are allowable to donors only to the extent their contributions exceed the value of the goods or services received in exchange. Ticket purchases and similar payments in conjunction with fundraising events may not necessarily qualify as fully deductible contributions, depending on the circumstances. If your organization conducts fundraising events such as benefit dinners, shows, membership drives, etc., where something of value is received, you are required to provide a written statement informing donors of the fair market value of the specific items or services you provided in exchange for contributions of more than \$75.

You should provide the written disclosure statement in advance of any event, determine the fair market value of any benefit received, determine the amount of the contribution that is deductible, and state this information in your fundraising materials such as solicitations, tickets, and receipts. The amount of the contribution that is deductible is limited to the excess of any money (and the value of any property other than money) contributed by the donor less the value of goods or services provided by the charity. Your disclosure statement should be made, no later than, at the time payment is received. Subject to certain exceptions, your disclosure responsibility applies to any fundraising circumstances where each complete payment, including the contribution portion, exceeds \$75. For additional information, see Publication 1771 and Publication 526, Charitable Contributions.

EXCESS BENEFIT TRANSACTIONS

Excess benefit transactions are governed by section 4958 of the Code. Excess benefit transactions involve situations where a section 501(c)(3) organization provides an unreasonable benefit to a person who is in a position to exercise substantial influence over the organization's affairs. If you believe there may be an excess benefit transaction involving your organization, you should report the transaction on Form 990 or 990-EZ. Additional information can be found in the instructions for Form 990 and Form 990-EZ, or you may call our

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toll free number to obtain additional information on how to correct and report this transaction.

EMPLOYMENT TAXES

If you have employees, you are subject to income tax withholding and the social security taxes imposed under the Federal Insurance Contribution Act (FICA). You are required to withhold Federal income tax from your employee's wages and you are required to pay FICA on each employee who is paid more than \$100 in wages during a calendar year. To know how much income tax to withhold, you should have a Form W-4, Employee's Withholding Allowance Certificate, on file for each employee. Organizations described in section 501(c)(3) of the Code are not required to pay Federal Unemployment Tax (FUTA).

Employment taxes are reported on Form 941, Employer's Quarterly Federal Tax Return. The requirements for withholding, depositing, reporting and paying employment taxes are explained in Circular E, Employer's Tax Guide, (Publication 15), and Employer's Supplemental Tax Guide, (Publication 15-A). These publications explain your tax responsibilities as an employer.

CHURCHES

Churches may employ both ministers and church workers. Employees of churches or church-controlled organizations are subject to income tax withholding, but may be exempt from FICA taxes. Churches are not required to pay FUTA tax. In addition, although ministers are generally common law employees, they are not treated as employees for employment tax purposes. These special employment tax rules for members of the clergy and religious workers are explained in Publication 517, Social Security and Other Information for Members of the Clergy and Religious Workers. Churches should also consult Publications 15 and 15-A. Publication 1828, Tax Guide for Churches and Religious Organizations, also discusses the various benefits and responsibilities of these organizations under Federal tax law.

PUBLIC CHARITY STATUS

Every organization that qualifies for tax-exemption as an organization described in section 501(c)(3) is a private foundation unless it falls into one of the categories specifically excluded from the definition of that term [referred to in section 509(a)(1), (2), (3), or (4)]. In effect, the definition divides these organizations into two classes, namely private foundations and public charities.

Public charities are generally those that either have broad public support or actively function in a supporting relationship to those organizations.

Public charities enjoy several advantages over private foundations. There are certain excise taxes that apply to private foundations but not to public charities. A private foundation must also annually file Form 990-PF, Return of Private Foundation, even if it had no revenue or expenses.

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