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Internal Revenue Service
Director, Exempt Organizations
Rulings and Agreements

Department of the Treasury
P.O. Box 2508, EODQA Room 7008
Cincinnati, OH 45201

Date: APR 01 2004

Employer Identification Number:

UIL: 501.00-00

Person to Contact - I.D.
Number:

Contact Telephone Numbers:
Phone
Fax

Dear Sir or Madam:

We have considered your application for recognition of exemption from Federal income tax under the provisions of section 501(c)(3) of the Internal Revenue Code of 1986 and its applicable Income Tax Regulations. Based on the available information, we have determined that you do not qualify for the reasons set forth on Enclosure I.

Consideration was given to whether you qualify for exemption under other subsections of section 501(c) of the Code. However, we have concluded that you do not qualify under another subsection.

As your organization has not established exemption from Federal income tax, it will be necessary for you to file an annual income tax return on Form 1041 if you are a Trust, or Form 1120 if you are a corporation or an unincorporated association. Contributions to you are not deductible under section 170 of the Code.

If you are in agreement with our proposed denial, please sign and return one copy of the enclosed Form 6018, Consent to Proposed Adverse Action.

You have the right to protest this proposed determination if you believe it is incorrect. To protest, you should submit a written appeal giving the facts, law and other information to support your position as explained in the enclosed Publication 892, "Exempt Organizations Appeal Procedures for Unagreed Issues." The appeal must be submitted within 30 days from the date of this letter and must be signed by one of your principal officers. You may request a hearing with a member of the office of the Regional Director of Appeals when you file your appeal. If a hearing is requested, you will be contacted to arrange a date for it. The hearing may be held at the Regional Office or, if you request, at any mutually convenient District Office. If you are to be represented by someone who is not one of your principal officers, he or she must file a proper power of attorney and otherwise qualify under our Conference and Practice Requirements as set forth in Section 601.502 of the Statement of Procedural Rules. See Treasury Department Circular No. 230.

DR-053-2004

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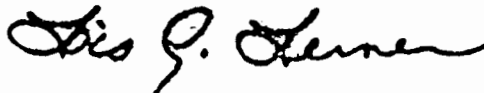
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If you do not protest this proposed determination in a timely manner, it will be considered by the Internal Revenue Service as a failure to exhaust available administrative remedies. Section 7428(b)(2) of the Internal Revenue Code provides, in part, that:

A declaratory judgement or decree under this section shall not be issued in any proceeding unless the Tax Court, the Claims Court, or the district court of the United States for the District of Columbia determines that the organization involved has exhausted administrative remedies available to it within the Internal Revenue Service.

If we do not hear from you within the time specified, this will become our final determination. In that event, appropriate State officials will be notified of this action in accordance with the provisions of section 6104(c) of the Code.

Sincerely,



Director, Exempt Organizations
Rulings and Agreements

cc:

Enclosures: 3
Enclosure I
Form 6018
Publication 892

ENCLOSURE 1

ISSUE:

Does the organization qualify for exemption from Federal income tax as an organization described in section 501(c)(3) of the Internal Revenue Code?

FACTS:

The organization incorporated under the non-profit laws of the _____ on _____ under the name of the _____ The Articles contained the following provisions:

•

•

•

The organization amended its Articles of Incorporation on _____ by making the following changes:

•

•

The corporate bylaws contain the following provisions:

•

Form 1023 includes the following statements:

The organization is formed for charitable and educational purposes to provide assistance to individuals and their families who suffer afflictions from Lou Gherig's disease and other diseases as well as to engage in education and research to further the general public's and the medical community's understanding and or prevention and or treatment of Lou Gherig's disease.

In support of its purposes, the organization's activities have consisted only of the program called _____ The program involves the following:

- The selection of an individual to be treated and the results of the experimental research to be shared with the medical community and the general public.
- The program will involve the use of certain types of alternative medicines.
- The individual selected will receive 24 hour assisted care (caregivers/nursing), shelter and food (lodging and living expenses).

It is indicated that the program would be conducted, administered and overseen by certain doctors and healthcare practitioners.

The director and officer positions are occupied as follows:

Director and President -
 Director and Secretary -
 Director and Treasurer -

In response to inquiries regarding the organization's activities, the following information has been provided:

(The date of the organization's response from its legal representative is shown in parentheses.)

- The organization has been funded primarily by individual contributions (October 10, 2003) which include several substantial contributors (December 1, 2003). A partial list of contributors was provided. (December 4, 2003)
- All fundraising activities and the solicitation of contributions have been publicized by word of mouth (October 10, 2003) and some e-mail communication. (January 19, 2004)
- The organization has no literature to provide.
- is the individual the organization chose to assist. (November 7, 2003)
- is the brother of Director/Treasurer - is also a friend of Director/President - . (December 1, 2003)
- No formal application process was utilized by the organization to solicit candidates for aid. (December 1, 2003) However, subsequent correspondence (January 19, 2004) indicates that other "applicants" were considered, however, no documentation was provided.
- The eligibility of the recipient for aid considered the degree of the recipient's disability, financial condition, age of the recipient and the likelihood of survival. (December 1, 2003)
- was chosen by a majority vote of the unrelated members of the board. (December 1, 2003)
- The first fundraiser held by the organization occurred after was chosen as the recipient of aid to be provided. Contributors and those in attendance were informed that would be the beneficiary. (December 1, 2003)

- Support of _____ began in December 2002. Thus far, all organization funds other than administrative and fund-raising costs have been used toward the support of _____

- The organization has not engaged in any formal research activities due to limited finances (i.e. hiring of researchers, etc). (October 10, 2003, November 7, 2003)

LAW:

Section 501(c)(3) of the Internal Revenue Code describes certain organizations exempt from income tax under section 501(a) and reads in part as follows:

"(3) Corporations, and any community chest, fund or foundation organized and operated exclusively for religious, charitable, scientific, testing for public safety, literary or educational purposes, or to foster national or international amateur sports competition (but only if no part of its activities involve the provision of athletic facilities or equipment), or for the prevention of cruelty to children or animals, no part of the net earnings of which inures to the benefit of any private shareholder or individual, no substantial part of the activities of which is carrying on propaganda, or otherwise attempting, to influence legislation, (except as otherwise provided in subsection (h)), and which does not participate in or intervene in (including the publishing or distributing of statements), any political campaign on behalf of (or in opposition to) any candidate for public office."

Section 1.501(c)(3)-1(a)(1) of the Income Tax Regulations states that, in order to be exempt as an organization described in section 501(c)(3) of the Code, an organization must be both organized and operated exclusively for one or more of the purposes specified in such section. If an organization fails to meet either the organizational test or the operational test, it is not exempt.

Section 1.501(c)(3)-1(b)(1)(i) of the income tax Regulations provides that an organization is organized exclusively for one or more exempt purposes only if its articles of organization (a) limit the purposes of such organization to one or more exempt purposes; and (b) do not expressly empower the organization to engage otherwise than an insubstantial part of its activities, in activities which in themselves are not in furtherance of one or more exempt purpose.

Section 1.501(c)(3)-1(c)(1) of the income tax Regulations provides that an organization will be regarded as "operated exclusively" for one or more exempt purposes only if it engages primarily in activities which accomplish one or more of such exempt purposes specified in section 501(c)(3). An organization will not be so regarded if more than an insubstantial part of its activities is not in furtherance of an exempt purpose.

Section 1.501(c)(3)-1(d)(ii) of the income tax Regulations states that an organization is not organized or operated exclusively for one or more exempt purposes unless it serves a public rather than a private interest. Thus to meet the requirements, an organization must establish that it is not organized or operated for the benefit of a private interest, such as designated individuals, the creator or his family, shareholders or the organization, or persons controlled, directly or indirectly, by such private interests.

Section 1.501(c)(3)-1(d)(2) of the Income Tax Regulations defines the term "charitable". Although used in section 501(c)(3) in its generally accepted legal sense, the term charitable is broad and includes: Relief of the poor and distressed or of the underprivileged; advancement of religion; advancement of education or science; erection or maintenance of public buildings, monuments, or works; lessening the burdens of Government; and promotion of social welfare by organizations designed to accomplish any of the above purposes or (i) to lessen neighborhood tensions; (ii) to eliminate prejudice and discrimination; (iii) to defend human and civil rights secured by law; or (iv) combat community deterioration and juvenile delinquency.

Section 1.501(c)(3)-1(d)(3)(i)(a) of the income tax Regulations defines the term "educational" as including the instruction or training of the individual for the purpose of improving or developing his capabilities.

In American Campaign Academy v. Commissioner, 92 TC 1053 (1989), the organization conducted an educational program for professional political campaign workers. It furnished classrooms, materials, and qualified instructors. Admission was through a competitive application process. The Service argued that the Academy substantially benefited the private interests of Republican party entities and candidates, thereby advancing a nonexempt private purpose. The relationship between the Academy and "Republican party entities and candidates" was not one of control, although the Academy was an outgrowth of a training program operated by National Republican Congressional Committee. The Academy argued that the prohibition against private benefit is limited to situations in which an organization's insiders are benefited. The Tax Court, however, disagreed with this view, and stated that an organization's conferral of benefits on disinterested persons may cause it to serve a private interest within the meaning of section 1.501(c)(3)-1(d)(1)(ii). Private benefit was defined as "nonincidental benefits conferred on disinterested persons that serve private interests."

Better Business Bureau of Washington D.C., Inc. v. United States, 326 U.S. 279 (1945), held that the presence of a single nonexempt purpose, if substantial in nature, will preclude tax exemption under section 501(c)(3) of the Code.

In The Church of the Living Tree v. Commissioner, T.C. Memo 1996-291 (1996), it was determined that activities concerning papermaking (industry) constituted a substantial non-exempt purpose which did not entitle the organization to exemption under 501(c)(3) and constituted a benefit to private individuals.

In Schoger Foundation v Commissioner, 76 T.C. 380 (1981) it was held that if an activity serves a substantial nonexempt purpose, the organization does not qualify for exemption even if the activity also furthers an exempt purpose.

In Wendy L Parker Rehabilitation Foundation Inc v. Commissioner, TC Memo 1986-348, a foundation formed to aid coma victims was found not to be exempt under section 501(c)(3) as one of those aided was a family member of a founding organization director which constituted a private benefit. Approximately 30% of the organization's net income was expected to be distributed to aid the family coma victim. The Court found that the family coma victim was a substantial beneficiary of the foundation's funds. It also noted that such

distributions relieved the family of the economic burden of providing medical and rehabilitation care for their family member and, therefore, constituted inurement to the benefit of private individuals.

ANALYSIS:

Section 501(c)(3) of the Code sets forth two main tests for qualification for exempt status. An organization must be both organized and operated exclusively for purposes described in section 501(c)(3).

The organization has satisfied the organizational test.

To satisfy the operational test, the organization must be operated exclusively for one or more exempt purposes. Furthermore, the organization's activities must not constitute a private benefit.

The organization has applied for exemption as a charitable and educational organization. The organization's focus has been to assist an individual with Lou Gherig's disease (ALS). The program, called _____ by the organization, is described as

The program involves the use of alternative medicine treatments on a selected individual, the results of which will be shared with the medical community and the general public. As part of the program, the selected individual receives 24 hour assisted care and the provision of food and shelter.

The organization contends that the Advance Research program constitutes research activity and thus is charitable and educational under section 501(c)(3).

The organization chose _____ as the recipient of aid. It is the position of the Service that the financial aid given to _____ does not constitute an exempt purpose under section 501(c)(3) of the Code.

Section 1.501(c)(3)-1(d)(ii) of the income tax Regulations states that an organization is not organized or operated exclusively for one or more exempt purposes unless it serves a public rather than a private interest. It has not been demonstrated that the organization is operated for public

purposes. It appears that the organization is operated for private interests based on the facts that [redacted] is the brother of organization Director and Treasurer - as well as a friend of organization Director and President -

No formal application process was utilized or considered by the organization to solicit candidates for aid. [redacted] was chosen as the recipient for aid and although the organization indicates that only unrelated parties voted on the selection, there is no documentation that anyone other than [redacted] was seriously considered as an "applicant". Additionally, the organization was originally incorporated under the name of [redacted]. The organization began financial support of [redacted] shortly after incorporation, providing for his 24 hour nursing care, food, shelter, uninsured medical expenses and certain personal expenses. According to the organization's responses, initial fundraising identified [redacted] as the recipient of the aid. The organization has no publicity material or other written records concerning subsequent fundraising that would support a claim that [redacted] was not the designated recipient of the proceeds from such events or solicitations.

The organization is similar to the one described in the Wendy L. Parker Rehabilitation Foundation case. Its assets are used to aid a family member of the Board of Directors; this usage of a substantial portion of the organization's funds constitutes a private benefit.

The organization has offered that both [redacted] and [redacted] will step down from their positions as directors and officers. The Service does not consider such actions as corrective. The conferral of aid to [redacted] would still be considered private benefit. As ruled in American Campaign Academy v. Commissioner, 92 TC 1053 (1989), private benefit was defined as "nonincidental benefits conferred on disinterested persons that serve private interests." As noted above, the Court found that an organization's conferral of benefits on disinterested persons might cause it to serve a private interest within the meaning of section 1.501(c)(3)-1(d)(1)(ii).

While an organization may permissibly limit financial assistance to a small number of beneficiaries based on availability of funds, there must be a showing of an objective selection process that is absent in this case.

The Service holds that the organization's project does not constitute scientific research within the meaning of section 501(c)(3) of the Code. The organization stated several times that it did not have the resources to engage in other activities such as sponsoring research and would hold off such activity such as the hiring of a medical researcher and assistants until more funding could be secured. The organization's activities have been limited to the provision of financial assistance to . The organization contends (in the January 19, 2004 correspondence) that undergoing of various types of treatment (embryonic neuronal stem cell treatments, cord blood stem cell treatments and proposed IGF-2 treatments) prescribed by physicians and his medical response to such treatments constitutes substantial research activities related to the cure of ALS. The organization lists several doctors connected to the IGF treatments and research; however, there is no apparent connection with the organization, and the organization is not funding any research project(s). The Service does not agree that the organization's provision of financial aid while receives prescribed medical treatment constitutes medical research. While may be one of a number of persons participating in tests of different alternative treatments and therapies for ALS patients, the organization is neither sponsoring such research nor paying expenses for any other person receiving such treatments. While the organization contends that it has a broader purpose of furthering medical research and that it would aid more individuals if it had more funds, its actions to date do not appear to support this argument.

It appears that the organization was created and operates for the purpose of providing financial support to a designated individual, to receive benefits, thus serving a private interest. Therefore, the organization fails to further exempt purposes under Section 1.501(c)(3)-1(c)(1) of income tax regulations.

As stated in Better Business Bureau of Washington D.C., Inc. v. United States 326 U.S. 279 (1945), the presence of a single nonexempt purpose, if substantial in nature, will destroy a claim for exemption regardless of the number or importance of truly exempt purposes.

The organization is also similar to the organization in Schoger Foundation v. Commissioner, 76 T.C. 380 (1981), whereby it was held that if an activity serves a substantial

nonexempt purpose, the organization does not qualify for exemption even if the activity also furthers an exempt purpose.

Also, like the organization in The Church of the Living Tree v. Commissioner, T.C. Memo 1996-291 (1996) the organization's activities which constituted substantial non-exempt purposes did not entitle the organization to exemption under 501(c)(3) and constituted a benefit to private individuals.

The organization is not operated exclusively for exempt purposes and fails to meet Section 1.501(c)(3)-1(a)(1) of the Income Tax Regulations that states that in order to be exempt as an organization described in section 501(c)(3) of the Code, an organization must be both organized and operated exclusively for one or more of the purposes specified in such section. If an organization fails to meet either the organizational test or the operational test, it is not exempt.

Conclusion:

It is the opinion of the Internal Revenue Service, based on the information submitted, that you do not meet the requirements for exemption as an organization described in section 501(c)(3) of the Internal Revenue Code because you are not operating in compliance with section 501(c)(3).

Form 6018
(Rev. Aug. 1983)

Department of the Treasury - Internal Revenue Service
Consent to Proposed Adverse Action
(All references are to the Internal Revenue Code)

Case Number
603127046

Date of Latest Determination Letter

Employer Identification Number

Date of Proposed Adverse Action Letter

APR 01 2004

Name and Address of Organization

I consent to the proposed adverse action relative to the above organization as shown below. I understand that if Section 7428, Declaratory Judgements Relating to Status and Classification of Organizations under Section 501(c)(3), etc. applies, I have the right to protest the proposed adverse action.

NATURE OF ADVERSE ACTION

Denial of exemption

Revocation of exemption, effective.

Modification of exemption from section 501(c)() to section 501(c)(), effective

Classification as a private foundation described in section 509(a), effective ****

Classification as an private operating foundation described in sections 509(a) and 4942(j)(3), effective for

Classification as an organization described in section 509(a)(), effective

Classification as an organization described in section 170(b)(1)(A)(), effective

If you agree to the adverse action shown above, please sign and return this consent. You should keep a copy for your records.

If you sign this consent before you have exhausted your administrative appeal rights, you may lose your rights to a declaratory judgement under section 7428.

(Signature instructions on Back)

Name of Organization:

Signature and Title

Date

Signature and Title

Date

20044032E

Form 6018 Instructions

Do not use this consent if the organization is subject to the declaratory provisions of section 7428 and has submitted a protest of adverse action.

This consent should be signed by hand (do not type, stamp or print) with the name of the organization, followed by the signature(s) and titles(s) of the person(s) authorized to sign on behalf of the organization. An attorney or agent may sign provided the action is specifically authorized by a power of attorney. If the power of attorney was not previously filed, please include it with this form.