

"Public Disclosure Copy"

Form 990

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2008

Open to Public Inspection

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

The organization may have to use a copy of this return to satisfy state reporting requirements.

Department of the Treasury Internal Revenue Service

A For the 2008 calendar year, or tax year beginning 7/1/2008, and ending 6/30/2009

B Check if applicable: Address change, Name change, Initial return, Termination, Amended return, Application pending. C Name of organization: Alpha-1 Antitrypsin Deficiency Association. D Employer identification number: 41-1712790. E Telephone number: (800) 521-3025. G Gross receipts \$: 1,265,467.

F Name and address of principal officer: Marlene S. Erven 2937 SW 27th Ave Suite 106, Miami, FL 33133-3772. H(a) Is this a group return for affiliates? Yes X No. H(b) Are all affiliates included? Yes No. H(c) Group exemption number.

I Tax-exempt status: X 501(c) (3) (insert no.) 4947(a)(1) or 527. J Website: www.alpha1.org. K Type of organization: X Corporation. L Year of formation: 1991. M State of legal domicile: MN.

Part I Summary

Table with 3 columns: Description, Prior Year, Current Year. Rows include: 1 Mission statement, 2-7 Governance, 8-12 Revenue, 13-19 Expenses, 20-22 Net Assets or Fund Balances.

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here: Signature of officer: Marlene S. Erven, Executive Director. Date: 10/5/2009.

Paid Preparer's Use Only: Preparer's signature: JOHN F. WARD, Date: 9/27/2009, Check if self-employed: X, Preparer's identifying number: 123-34-2624.

May the IRS discuss this return with the preparer shown above? (see instructions) X Yes No

Part III Statement of Program Service Accomplishments (see instructions)

1 Briefly describe the organization's mission:

The mission of the Alpha-1 Association is to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education, advocacy, and encourage participation in research. The mission has been accomplished with the assistance of more than 250 volunteers from the Alpha-1 Community. The Association has provided programs and services to more than 3,000 Alphas and family members in the year ended June 30, 2009.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?

Yes No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?

Yes No

If "Yes," describe these changes on Schedule O.

4 Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 272,810 including grants of \$ 15,940) (Revenue \$ 47,723)

The 2009 18th Annual National Education Conference, "The Bridge to a Healthier Tomorrow" was held on June 5-7, 2009. This conference was held in San Francisco, CA and was attended by a record number of patients and family members. Over 1/3 of the attendees were first time participants. The conference brings some of the leading Clinicians and Researchers in the Alpha-1 medical community and other health professionals as Speakers. The programs cover a wide range of medical education topics and supportive topics to inform and empower patients about their health. The Conference allows patients to network with other Alphas, become motivated to take charge of their health, participate in local support groups, awareness, outreach, or advocacy programs. The last three years of presentations are available on our website at www.alpha1.org. The conference was rated a 4.75 out of 5 by this year's attendees.

4b (Code:) (Expenses \$ 183,675 including grants of \$ 0) (Revenue \$ 0)

National Education Series - This series of one day patient educational programs has been conducted since 1999 as a collaborative effort with the Alpha-1 Foundation. This year the programs were held in Raleigh, NC, Las Vegas, NV, Boise, ID, Lebanon, NH, Los Angeles, CA and Jacksonville, FL. The series has provided access to current medical information and resources to thousands of Alphas, their families, and caregivers. There is no cost to the participants other than their personal travel expenses. In many cases these programs are planned in conjunction with Alpha-1 "Foundation-affiliated" Clinical Resource Centers. A dinner or event is held in conjunction with each Day to provide Alphas and their families an opportunity to interact with other Alphas, Speakers, and Exhibitors. Continuing education credits are available to respiratory therapists and genetic counselors who attend these programs. More than 100 presentations from this series are on our website and available for viewing at www.alpha1.org.

4c (Code:) (Expenses \$ 127,397 including grants of \$ 18,159) (Revenue \$ 0)

Patient Support Network- The Alpha-1 Support Group Network consists of 75 + Support Groups and four Virtual Support Groups. Support resources are also provided by a Patient Hot Line and Peer Guide Referral program. Support groups are committed to improving the quality of life of individuals and their families affected by Alpha-1. Four new Virtual Support Groups were established this fiscal year. They are Alpha-1 Families, Transplant, Caregivers, and Alpha-1 Phone Buddies. A Support Group Leadership Training was held on June 7, 2009 bringing together 41 Support Group leaders for face to face training. In addition, monthly telecalls are held for Support Group Leaders to provide ongoing communication and education. Support Group Leaders reached more than 1500 patients and families with programs and services, the National Patient Hotline received approximately 600 calls, and Virtual Support Groups reached about 100 patients and family members.

4d Other program services. (Describe in Schedule O.)

(Expenses \$ 280,291 including grants of \$ 12,319) (Revenue \$ 26,100)

4e Total program service expenses ▶ \$ 864,173 (Must equal Part IX, Line 25, column (B).)

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors?	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities? If "Yes," complete Schedule C, Part II	X	
5 Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If "Yes," complete Schedule C, Part III		
6 Did the organization maintain any donor advised funds or any accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV		X
10 Did the organization hold assets in term, permanent, or quasi-endowments? If "Yes," complete Schedule D, Part V		X
11 Did the organization report an amount in Part X, lines 10, 12, 13, 15, or 25? If "Yes," complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable	X	
12 Did the organization receive an audited financial statement for the year for which it is completing this return that was prepared in accordance with GAAP? If "Yes," complete Schedule D, Parts XI, XII, and XIII	X	
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		X
14a Did the organization maintain an office, employees, or agents outside of the U.S.?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the U.S.? If "Yes," complete Schedule F, Part I		X
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If "Yes," complete Schedule F, Part II		X
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If "Yes," complete Schedule F, Part III		X
17 Did the organization report more than \$15,000 on Part IX, column (A), line 11e? If "Yes," complete Schedule G, Part I		X
18 Did the organization report more than \$15,000 total on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II		X
19 Did the organization report more than \$15,000 on Part VIII, line 9a? If "Yes," complete Schedule G, Part III		X
20 Did the organization operate one or more hospitals? If "Yes," complete Schedule H		X
21 Did the organization report more than \$5,000 on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II		X
22 Did the organization report more than \$5,000 on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	X	
23 Did the organization answer "Yes" to Part VII, Section A, questions 3, 4, or 5? If "Yes," complete Schedule J		X
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer questions 24b-24d and complete Schedule K. If "No," go to question 25		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I		X
b Did the organization become aware that it had engaged in an excess benefit transaction with a disqualified person from a prior year? If "Yes," complete Schedule L, Part I		X
26 Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If "Yes," complete Schedule L, Part II		X
27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, or substantial contributor, or to a person related to such an individual? If "Yes," complete Schedule L, Part III		X

Part IV Checklist of Required Schedules (continued)

		Yes	No
28	During the tax year, did any person who is a current or former officer, director, trustee, or key employee:		
a	Have a direct business relationship with the organization (other than as an officer, director, trustee, or employee), or an indirect business relationship through ownership of more than 35% in another entity (individually or collectively with other person(s) listed in Part VII, Section A)? <i>If "Yes," complete Schedule L, Part IV.</i>		X
b	Have a family member who had a direct or indirect business relationship with the organization? <i>If "Yes," complete Schedule L, Part IV.</i>		X
c	Serve as an officer, director, trustee, key employee, partner, or member of an entity (or a shareholder of a professional corporation) doing business with the organization? <i>If "Yes," complete Schedule L, Part IV.</i>		X
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M.</i>		X
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M.</i>		X
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I.</i>		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II.</i>		X
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I.</i>		X
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1.</i>		X
35	Is any related organization a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2.</i>		X
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2.</i>		X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI.</i>		X

Part V Statements Regarding Other IRS Filings and Tax Compliance

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096, Annual Summary and Transmittal of U.S. Information Returns. Enter -0- if not applicable		
	1a 3		
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
	1b 0		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	X	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
	2a 7		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to <i>e-file</i> this return. (see instructions)	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?	X	
b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O	X	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
b	If "Yes," enter the name of the foreign country: ▶ _____ See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes," to question 5a or 5b, did the organization file Form 8886-T, Disclosure by Tax-Exempt Entity Regarding Prohibited Tax Shelter Transaction?		
	5c		
6a	Did the organization solicit any contributions that were not tax deductible?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
	6b		
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization provide goods or services in exchange for any quid pro quo contribution of more than \$75?		X
	7a		
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
	7b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
	7c		
d	If "Yes," indicate the number of Forms 8282 filed during the year		
	7d		
e	Did the organization, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
	7e		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
	7f		
g	For all contributions of qualified intellectual property, did the organization file Form 8899 as required?		X
	7g		
h	For contributions of cars, boats, airplanes, and other vehicles, did the organization file a Form 1098-C as required?		X
	7h		
8	Section 501(c)(3) and other sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a fund maintained by a sponsoring organization, have excess business holdings at any time during the year?		
	8		
9	Section 501(c)(3) and other sponsoring organizations maintaining donor advised funds.		
a	Did the organization make any taxable distributions under section 4966?		
	9a		
b	Did the organization make a distribution to a donor, donor advisor, or related person?		
	9b		
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12		
	10a		
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
	10b		
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders		
	11a		
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)		
	11b		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
	12a		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year		
	12b		

