

Return of Organization Exempt From Income Tax

2005

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

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

Form 990 header section A through L, including organization name (ADULT CONGENITAL HEART ASSOCIATION), EIN (04-3447959), and address (6757 GREENE ST, PHILADELPHIA, PA 19119).

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (See Instructions)

Main table with 21 rows for revenue and expenses. Revenue total is 128,675. Expenses total is 106,371. Net assets at end of year is 52,819.

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Part II Statement of Functional Expenses All organizations must complete column (A). Columns (B), (C), and (D) are required for section 501(c)(3) and (4) organizations and section 4947(a)(1) nonexempt charitable trusts but optional for others

Do not include amounts reported on line 6b, 8b, 9b, 10b, or 16 of Part I		(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
22 Grants and allocations (att sch) (cash \$ _____ non-cash \$ _____) If this amount includes foreign grants, check here <input type="checkbox"/>	22				
23 Specific assistance to individuals (att sch)	23				
24 Benefits paid to or for members (att sch)	24				
25 Compensation of officers, directors, etc	25	0.	0.	0.	0.
26 Other salaries and wages	26	3,984.	3,387.	398.	199.
27 Pension plan contributions	27				
28 Other employee benefits	28	5,157.	4,384.	271.	502.
29 Payroll taxes	29	454.	387.	45.	22.
30 Professional fundraising fees	30				
31 Accounting fees	31	9,592.	3,187.	6,405.	0.
32 Legal fees	32				
33 Supplies	33	5,868.	4,938.	639.	291.
34 Telephone	34	1,600.	1,360.	160.	80.
35 Postage and shipping	35	687.	584.	69.	34.
36 Occupancy	36	2,100.	1,785.	210.	105.
37 Equipment rental and maintenance	37	3,172.	2,696.	317.	159.
38 Printing and publications	38	1,176.	999.	118.	59.
39 Travel	39	5,868.	5,868.	0.	0.
40 Conferences, conventions, and meetings	40	21,309.	21,309.	0.	0.
41 Interest	41				
42 Depreciation, depletion, etc (attach schedule)	42				
43 Other expenses not covered above (itemize)					
a <u>Consultants</u>	43a	3,563.	3,563.	0.	0.
b <u>Insurance</u>	43b	2,901.	2,466.	290.	145.
c <u>Passport project</u>	43c	9,984.	9,984.	0.	0.
d <u>Web upgrade project</u>	43d	8,616.	8,616.	0.	0.
e <u>Newsletter expenses</u>	43e	8,358.	8,358.	0.	0.
f <u>Other program costs</u>	43f	2,249.	2,249.	0.	0.
g <u>See Other Expenses Stmt</u>	43g	9,733.	6,085.	0.	3,648.
44 Total functional expenses. Add lines 22 through 43 (Organizations completing columns (B) - (D), carry these totals to lines 13 - 15)	44	106,371.	92,205.	8,922.	5,244.

Joint Costs. Check if you are following SOP 98-2.

Are any joint costs from a combined educational campaign and fundraising solicitation reported in (B) Program services? Yes No
 If 'Yes,' enter (i) the aggregate amount of these joint costs \$ _____, (ii) the amount allocated to Program services \$ _____; (iii) the amount allocated to Management and general \$ _____, and (iv) the amount allocated to Fundraising \$ _____

Part III Statement of Program Service Accomplishments

Form 990 is available for public inspection and, for some people, serves as the primary or sole source of information about a particular organization. How the public perceives an organization in such cases may be determined by the information presented on its return. Therefore, please make sure the return is complete and accurate and fully describes, in Part III, the organization's programs and accomplishments.

What is the organization's primary exempt purpose? ▶ <u>Advocacy of Adult Congenital Heart Issues</u> All organizations must describe their exempt purpose achievements in a clear and concise manner. State the number of clients served, publications issued, etc. Discuss achievements that are not measurable (Section 501(c)(3) and (4) organizations and 4947(a)(1) nonexempt charitable trusts must also enter the amount of grants and allocations to others.)	Program Service Expenses (Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts, but optional for others.)
a Educational Resources - See Attached ----- ----- ----- ----- ----- (Grants and allocations \$ 0.) If this amount includes foreign grants, check here ▶ <input type="checkbox"/>	37,180.
b Patient-Family Conferences - See Attached ----- ----- ----- ----- ----- (Grants and allocations \$ 0.) If this amount includes foreign grants, check here ▶ <input type="checkbox"/>	30,196.
c Outreach & Advocacy - See Attached ----- ----- ----- ----- ----- (Grants and allocations \$ 0.) If this amount includes foreign grants, check here ▶ <input type="checkbox"/>	15,524.
d Organizational Development - See Attached ----- ----- ----- ----- ----- (Grants and allocations \$ 0.) If this amount includes foreign grants, check here ▶ <input type="checkbox"/>	9,305.
e Other program services (Grants and allocations \$) If this amount includes foreign grants, check here ▶ <input type="checkbox"/>	
f Total of Program Service Expenses (should equal line 44, column (B), Program services) ▶	92,205.

BAA

Part IV Balance Sheets (See Instructions)

Note: Where required, attached schedules and amounts within the description column should be for end-of-year amounts only

		(A) Beginning of year		(B) End of year
ASSETS	45 Cash – non-interest-bearing		45	
	46 Savings and temporary cash investments	28,737.	46	50,159.
	47a Accounts receivable	47a 2,469.		
	b Less allowance for doubtful accounts	47b	245.	47c 2,469.
	48a Pledges receivable	48a		
	b Less allowance for doubtful accounts	48b		48c
	49 Grants receivable		49	
	50 Receivables from officers, directors, trustees, and key employees (attach schedule)		50	
	51a Other notes & loans receivable (attach sch)	51a		
	b Less: allowance for doubtful accounts	51b		51c
	52 Inventories for sale or use		52	
	53 Prepaid expenses and deferred charges		2,073.	53 1,285.
	54 Investments – securities (attach schedule)	<input type="checkbox"/> Cost <input type="checkbox"/> FMV		54
	55a Investments – land, buildings, & equipment basis	55a		
	b Less accumulated depreciation (attach schedule)	55b		55c
56 Investments – other (attach schedule)			56	
57a Land, buildings, and equipment, basis	57a			
b Less accumulated depreciation (attach schedule)	57b		57c	
58 Other assets (describe ▶ _____)			58	
59 Total assets (must equal line 74). Add lines 45 through 58		31,055.	59	53,913.
LIABILITIES	60 Accounts payable and accrued expenses		540.	60 1,094.
	61 Grants payable		61	
	62 Deferred revenue		62	
	63 Loans from officers, directors, trustees, and key employees (attach schedule)		63	
	64a Tax-exempt bond liabilities (attach schedule)		64a	
	b Mortgages and other notes payable (attach schedule)		64b	
	65 Other liabilities (describe ▶ _____)		65	
66 Total liabilities. Add lines 60 through 65		540.	66	1,094.
NET ASSETS OR FUND BALANCES	Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 67 through 69 and lines 73 and 74.			
	67 Unrestricted		30,515.	67 32,279.
	68 Temporarily restricted		68	20,540.
	69 Permanently restricted		69	
	Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 70 through 74			
	70 Capital stock, trust principal, or current funds		70	
	71 Paid-in or capital surplus, or land, building, and equipment fund		71	
	72 Retained earnings, endowment, accumulated income, or other funds		72	
73 Total net assets or fund balances (add lines 67 through 69 or lines 70 through 72, column (A) must equal line 19; column (B) must equal line 21)		30,515.	73	52,819.
74 Total liabilities and net assets/fund balances. Add lines 66 and 73		31,055.	74	53,913.

Part IV-A Reconciliation of Revenue per Audited Financial Statements with Revenue per Return (See instructions.)

		N/A
a	Total revenue, gains, and other support per audited financial statements	a
b	Amounts included on line a but not on Part I, line 12:	
	1 Net unrealized gains on investments	b1
	2 Donated services and use of facilities	b2
	3 Recoveries of prior year grants	b3
	4 Other (specify) _____	b4
	Add lines b1 through b4	b
c	Subtract line b from line a	c
d	Amounts included on Part I, line 12, but not on line a :	
	1 Investment expenses not included on Part I, line 6b	d1
	2 Other (specify) _____	d2
	Add lines d1 and d2	d
e	Total revenue (Part I, line 12). Add lines c and d	e

Part IV-B Reconciliation of Expenses per Audited Financial Statements with Expenses per Return

		N/A
a	Total expenses and losses per audited financial statements	a
b	Amounts included on line a but not on Part I, line 17:	
	1 Donated services and use of facilities	b1
	2 Prior year adjustments reported on Part I, line 20	b2
	3 Losses reported on Part I, line 20	b3
	4 Other (specify) _____	b4
	Add lines b1 through b4	b
c	Subtract line b from line a	c
d	Amounts included on Part I, line 17, but not on line a :	
	1 Investment expenses not included on Part I, line 6b	d1
	2 Other (specify) _____	d2
	Add lines d1 and d2	d
e	Total expenses (Part I, line 17). Add lines c and d	e

Part V-A Current Officers, Directors, Trustees, and Key Employees (List each person who was an officer, director, trustee, or key employee at any time during the year even if they were not compensated.) (See the instructions.)

(A) Name and address	(B) Title and average hours per week devoted to position	(C) Compensation (if not paid, enter -0-)	(D) Contributions to employee benefit plans and deferred compensation plans	(E) Expense account and other allowances
Amy Verstappen Philadelphia, PA	Exec. Director 20	0.	0.	0.
List Attached	Board Members 3	0.	0.	0.

Part VI Other Information (continued)		Yes	No
82 a Did the organization receive donated services or the use of materials, equipment, or facilities at no charge or at substantially less than fair rental value?	82 a	X	
b If 'Yes,' you may indicate the value of these items here. Do not include this amount as revenue in Part I or as an expense in Part II. (See instructions in Part III)			
83 a Did the organization comply with the public inspection requirements for returns and exemption applications?	83 a	X	
b Did the organization comply with the disclosure requirements relating to quid pro quo contributions?	83 b	X	
84 a Did the organization solicit any contributions or gifts that were not tax deductible?	84 a		X
b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		N/A	A
85 501(c)(4), (5), or (6) organizations. a Were substantially all dues nondeductible by members?	85 a	N/A	
b Did the organization make only in-house lobbying expenditures of \$2,000 or less?			
If 'Yes' was answered to either 85a or 85b, do not complete 85c through 85h below unless the organization received a waiver for proxy tax owed for the prior year.			
c Dues, assessments, and similar amounts from members	85 c		N/A
d Section 162(e) lobbying and political expenditures	85 d		N/A
e Aggregate nondeductible amount of section 6033(e)(1)(A) dues notices	85 e		N/A
f Taxable amount of lobbying and political expenditures (line 85d less 85e)	85 f		N/A
g Does the organization elect to pay the section 6033(e) tax on the amount on line 85f?	85 g	N/A	
h If section 6033(e)(1)(A) dues notices were sent, does the organization agree to add the amount on line 85f to its reasonable estimate of dues allocable to nondeductible lobbying and political expenditures for the following tax year?		N/A	A
86 501(c)(7) organizations Enter: a Initiation fees and capital contributions included on line 12	86 a		N/A
b Gross receipts, included on line 12, for public use of club facilities			
87 501(c)(12) organizations Enter: a Gross income from members or shareholders	87 a		N/A
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)			
88 At any time during the year, did the organization own a 50% or greater interest in a taxable corporation or partnership, or an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If 'Yes,' complete Part IX	88		X
89 a 501(c)(3) organizations Enter: Amount of tax imposed on the organization during the year under section 4911 ▶ <u>N/A</u> , section 4912 ▶ <u>N/A</u> ; section 4955 ▶ <u>N/A</u>			
b 501(c)(3) and 501(c)(4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year or did it become aware of an excess benefit transaction from a prior year? If 'Yes,' attach a statement explaining each transaction			X
c Enter. Amount of tax imposed on the organization managers or disqualified persons during the year under sections 4912, 4955, and 4958		▶	0.
d Enter. Amount of tax on line 89c, above, reimbursed by the organization		▶	0.
90 a List the states with which a copy of this return is filed ▶ <u>Pennsylvania</u>			
b Number of employees employed in the pay period that includes March 12, 2005 (See instructions.)		90 b	0
91 a The books are in care of ▶ <u>Management</u> Telephone number ▶ <u>(215) 849-1260</u> Located at ▶ <u>6757 Greene St., Suite 335, Phila, PA</u> ZIP + 4 ▶ <u>19119</u>			
b 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)? If 'Yes,' enter the name of the foreign country ▶ <u>N/A</u>		91 b	X
See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Statements			
c At any time during the calendar year, did the organization maintain an office outside of the United States? If 'Yes,' enter the name of the foreign country ▶ <u>N/A</u>		91 c	X
92 Section 4947(a)(1) nonexempt charitable trusts filing Form 990 in lieu of Form 1041 - Check here and enter the amount of tax-exempt interest received or accrued during the tax year		92	N/A

Part VII Analysis of Income-Producing Activities (See the instructions)

Note: Enter gross amounts unless otherwise indicated

	Unrelated business income		Excluded by section 512, 513, or 514		(E) Related or exempt function income
	(A) Business code	(B) Amount	(C) Exclusion code	(D) Amount	
93 Program service revenue					
a Conferences					6,953.
b					
c					
d					
e					
f Medicare/Medicaid payments					
g Fees & contracts from government agencies					
94 Membership dues and assessments					14,155.
95 Interest on savings & temporary cash invmnts			14	943.	
96 Dividends & interest from securities					
97 Net rental income or (loss) from real estate					
a debt-financed property					
b not debt-financed property					
98 Net rental income or (loss) from pers prop					
99 Other investment income					
100 Gain or (loss) from sales of assets other than inventory					
101 Net income or (loss) from special events					
102 Gross profit or (loss) from sales of inventory					
103 Other revenue: a					
b Merchandise			12	1,601.	
c					
d					
e					
104 Subtotal (add columns (B), (D), and (E))				2,544.	21,108.
105 Total (add line 104, columns (B), (D), and (E))					23,652.

Note: Line 105 plus line 1d, Part I, should equal the amount on line 12, Part I

Part VIII Relationship of Activities to the Accomplishment of Exempt Purposes (See the instructions)

Line No.	Explain how each activity for which income is reported in column (E) of Part VII contributed importantly to the accomplishment of the organization's exempt purposes (other than by providing funds for such purposes).
93a, 94	To provide education, outreach, advocacy and promotion of adult congenital heart issues.

Part IX Information Regarding Taxable Subsidiaries and Disregarded Entities (See the instructions) N/A

(A) Name, address, and EIN of corporation, partnership, or disregarded entity	(B) Percentage of ownership interest	(C) Nature of activities	(D) Total income	(E) End-of-year assets
	%			
	%			
	%			
	%			

Part X Information Regarding Transfers Associated with Personal Benefit Contracts (See the instructions)

a Did the organization, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? Yes No

b Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? Yes No

Note: If 'Yes' to (b), file Form 8870 and Form 4720 (see instructions)

Please Sign Here

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.

Signature of officer: Amy Verstapper Date: August 9, 2006

Type or print name and title: Amy Verstapper President/CEO

Paid Preparer's Use Only

Preparer's signature: Joseph P. Leonard CPA Date: 07/29/06 Check if self-employed:

Firm's name (or yours if self-employed), address, and ZIP + 4: SNYDER, DAITZ & COMPANY
1617 JOHN F. KENNEDY BLVD., SUITE 1035
PHILADELPHIA PA 19103

EIN: (215) 563-6141

Preparer's SSN or PTIN (See General Instruction W)

Phone no: (215) 563-6141

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

**Organization Exempt Under
Section 501(c)(3)**

(Except Private Foundation) and Section 501(e), 501(f), 501(k),
501(n), or 4947(a)(1) Nonexempt Charitable Trust
Supplementary Information — (See separate instructions.)

▶ **MUST be completed by the above organizations and attached to their Form 990 or 990-EZ.**

OMB No 1545 0047

2005

Name of the organization

ADULT CONGENITAL HEART ASSOCIATION

Employer identification number

04 - 3447959

Part I Compensation of the Five Highest Paid Employees Other Than Officers, Directors, and Trustees

(See instructions. List each one. If there are none, enter 'None'.)

(a) Name and address of each employee paid more than \$50,000	(b) Title and average hours per week devoted to position	(c) Compensation	(d) Contributions to employee benefit plans and deferred compensation	(e) Expense account and other allowances
NONE				
Total number of other employees paid over \$50,000 ▶		NONE		

Part II A Compensation of the Five Highest Paid Independent Contractors for Professional Services

(See instructions. List each one (whether individuals or firms) If there are none, enter 'None'.)

(a) Name and address of each independent contractor paid more than \$50,000	(b) Type of service	(c) Compensation
NONE		
Total number of others receiving over \$50,000 for professional services ▶		NONE

Part II B Compensation of the Five Highest Paid Independent Contractors for Other Services

(List each contractor who performed services other than professional services, whether individuals or firms. If there are none, enter 'None'. See instructions.)

(a) Name and address of each independent contractor paid more than \$50,000	(b) Type of service	(c) Compensation
NONE		
Total number of other contractors receiving over \$50,000 for other services ▶		NONE

Part III Statements About Activities (See instructions)

	Yes	No
<p>1 During the year, has the organization attempted to influence national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum? If 'Yes,' enter the total expenses paid or incurred in connection with the lobbying activities. ▶ \$ <u>491.</u> <u>0.</u></p> <p>(Must equal amounts on line 38, Part VI-A, or line i of Part VI-B.)</p> <p>Organizations that made an election under section 501(h) by filing Form 5768 must complete Part VI-A. Other organizations checking 'Yes' must complete Part VI-B AND attach a statement giving a detailed description of the lobbying activities SEE ATTACHED</p>	1	X
2 During the year, has the organization, either directly or indirectly, engaged in any of the following acts with any substantial contributors, trustees, directors, officers, creators, key employees, or members of their families, or with any taxable organization with which any such person is affiliated as an officer, director, trustee, majority owner, or principal beneficiary? (If the answer to any question is 'Yes,' attach a detailed statement explaining the transactions.)		
a Sale, exchange, or leasing of property?	2a	X
b Lending of money or other extension of credit?	2b	X
c Furnishing of goods, services, or facilities?	2c	X
d Payment of compensation (or payment or reimbursement of expenses if more than \$1,000)?	2d	X
e Transfer of any part of its income or assets?	2e	X
3a Do you make grants for scholarships, fellowships, student loans, etc? (If 'Yes,' attach an explanation of how you determine that recipients qualify to receive payments.)	3a	X
b Do you have a section 403(b) annuity plan for your employees?	3b	X
c During the year, did the organization receive a contribution of qualified real property interest under section 170(h)?	3c	X
4a Did you maintain any separate account for participating donors where donors have the right to provide advice on the use or distribution of funds?	4a	X
b Do you provide credit counseling, debt management, credit repair, or debt negotiation services?	4b	X

Part IV Reason for Non-Private Foundation Status (See instructions)

The organization is not a private foundation because it is: (Please check only **ONE** applicable box.)

- 5** A church, convention of churches, or association of churches. Section 170(b)(1)(A)(i).
- 6** A school. Section 170(b)(1)(A)(ii). (Also complete Part V.)
- 7** A hospital or a cooperative hospital service organization. Section 170(b)(1)(A)(iii).
- 8** A Federal, state, or local government or governmental unit. Section 170(b)(1)(A)(v).
- 9** A medical research organization operated in conjunction with a hospital. Section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state ▶ _____
- 10** An organization operated for the benefit of a college or university owned or operated by a governmental unit. Section 170(b)(1)(A)(iv). (Also complete the **Support Schedule** in Part IV-A.)
- 11a** An organization that normally receives a substantial part of its support from a governmental unit or from the general public. Section 170(b)(1)(A)(vi). (Also complete the **Support Schedule** in Part IV-A.)
- 11b** A community trust. Section 170(b)(1)(A)(vi). (Also complete the **Support Schedule** in Part IV-A.)
- 12** An organization that normally receives (1) more than 33-1/3% of its support from contributions, membership fees, and gross receipts from activities related to its charitable, etc., functions – subject to certain exceptions, and (2) no more than 33-1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Also complete the **Support Schedule** in Part IV-A.)
- 13** An organization that is not controlled by any disqualified persons (other than foundation managers) and supports organizations described in (1) lines 5 through 12 above; or (2) section 501(c)(4), (5), or (6), if they meet the test of section 509(a)(2). Check the box that describes the type of supporting organization. ▶ Type 1 Type 2 Type 3

Provide the following information about the supported organizations. (See instructions.)

(a) Name(s) of supported organization(s)	(b) Line number from above

- 14** An organization organized and operated to test for public safety. Section 509(a)(4). (See instructions.)

Part IV-A Support Schedule (Complete only if you checked a box on line 10, 11, or 12.) *Use cash method of accounting.*

Note: You may use the worksheet in the instructions for converting from the accrual to the cash method of accounting

Calendar year (or fiscal year beginning in)	(a) 2004	(b) 2003	(c) 2002	(d) 2001	(e) Total
15 Gifts, grants, and contributions received (Do not include unusual grants. See line 28.)	17,223.	24,398.	4,478.	9,955.	56,054.
16 Membership fees received	8,703.	4,675.	3,620.	785.	17,783.
17 Gross receipts from admissions, merchandise sold or services performed, or furnishing of facilities in any activity that is related to the organization's charitable, etc., purpose	41,632.	1,500.	6,068.	4,315.	53,515.
18 Gross income from interest, dividends, amounts received from payments on securities loans (section 512(a)(5)), rents, royalties, and unrelated business taxable income (less section 511 taxes) from businesses acquired by the organization after June 30, 1975					
19 Net income from unrelated business activities not included in line 18					
20 Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf					
21 The value of services or facilities furnished to the organization by a governmental unit without charge. Do not include the value of services or facilities generally furnished to the public without charge.					
22 Other income. Attach a schedule. Do not include gain or (loss) from sale of capital assets	851.				851.
23 Total of lines 15 through 22	68,409.	30,573.	14,166.	15,055.	128,203.
24 Line 23 minus line 17	26,777.	29,073.	8,098.	10,740.	74,688.
25 Enter 1% of line 23	684.	306.	142.	151.	

26 Organizations described on lines 10 or 11:

a Enter 2% of amount in column (e), line 24 ▶ 26a 1,494.

b Prepare a list for your records to show the name of and amount contributed by each person (other than a governmental unit or publicly supported organization) whose total gifts for 2001 through 2004 exceeded the amount shown in line 26a. Do not file this list with your return. Enter the total of all these excess amounts ▶ 26b 3,506.

c Total support for section 509(a)(1) test: Enter line 24, column (e) ▶ 26c 74,688.

d Add Amounts from column (e) for lines 18 _____ 19 _____ ▶ 26d 4,357.
 22 851. 26b 3,506.

e Public support (line 26c minus line 26d total) ▶ 26e 70,331.

f Public support percentage (line 26e (numerator) divided by line 26c (denominator)) ▶ 26f 94.17 %

27 Organizations described on line 12:

N/A a For amounts included in lines 15, 16, and 17 that were received from a 'disqualified person,' prepare a list for your records to show the name of, and total amounts received in each year from, each 'disqualified person.' Do not file this list with your return. Enter the sum of such amounts for each year
 (2004) _____ (2003) _____ (2002) _____ (2001) _____

b For any amount included in line 17 that was received from each person (other than 'disqualified persons'), prepare a list for your records to show the name of, and amount received for each year, that was more than the larger of (1) the amount on line 25 for the year or (2) \$5,000 (Include in the list organizations described in lines 5 through 11b, as well as individuals.) Do not file this list with your return. After computing the difference between the amount received and the larger amount described in (1) or (2), enter the sum of these differences (the excess amounts) for each year:
 (2004) _____ (2003) _____ (2002) _____ (2001) _____

c Add Amounts from column (e) for lines: 15 _____ 16 _____ ▶ 27c _____
 17 _____ 20 _____ 21 _____ ▶ 27d _____

d Add Line 27a total _____ and line 27b total _____ ▶ 27e _____

e Public support (line 27c total minus line 27d total) ▶ 27f _____

f Total support for section 509(a)(2) test. Enter amount from line 23, column (e) ▶ 27g _____ %

g Public support percentage (line 27e (numerator) divided by line 27f (denominator)) ▶ 27h _____ %

h Investment income percentage (line 18, column (e) (numerator) divided by line 27f (denominator)) ▶ 27h _____ %

28 Unusual Grants: For an organization described in line 10, 11, or 12 that received any unusual grants during 2001 through 2004, prepare a list for your records to show, for each year, the name of the contributor, the date and amount of the grant, and a brief description of the nature of the grant. Do not file this list with your return. Do not include these grants in line 15

Part V Private School Questionnaire (See instructions.)
 (To be completed ONLY by schools that checked the box on line 6 in Part IV)

		N/A	
		Yes	No
29	Does the organization have a racially nondiscriminatory policy toward students by statement in its charter, bylaws, other governing instrument, or in a resolution of its governing body?		
30	Does the organization include a statement of its racially nondiscriminatory policy toward students in all its brochures, catalogues, and other written communications with the public dealing with student admissions, programs, and scholarships?		
31	Has the organization publicized its racially nondiscriminatory policy through newspaper or broadcast media during the period of solicitation for students, or during the registration period if it has no solicitation program, in a way that makes the policy known to all parts of the general community it serves? If 'Yes,' please describe, if 'No,' please explain. (If you need more space, attach a separate statement.) ----- ----- -----		
32	Does the organization maintain the following.		
a	Records indicating the racial composition of the student body, faculty, and administrative staff?		
b	Records documenting that scholarships and other financial assistance are awarded on a racially nondiscriminatory basis?		
c	Copies of all catalogues, brochures, announcements, and other written communications to the public dealing with student admissions, programs, and scholarships?		
d	Copies of all material used by the organization or on its behalf to solicit contributions? If you answered 'No' to any of the above, please explain. (If you need more space, attach a separate statement.) ----- -----		
33	Does the organization discriminate by race in any way with respect to:		
a	Students' rights or privileges?		
b	Admissions policies?		
c	Employment of faculty or administrative staff?		
d	Scholarships or other financial assistance?		
e	Educational policies?		
f	Use of facilities?		
g	Athletic programs?		
h	Other extracurricular activities? If you answered 'Yes' to any of the above, please explain (If you need more space, attach a separate statement) ----- -----		
34 a	Does the organization receive any financial aid or assistance from a governmental agency?		
b	Has the organization's right to such aid ever been revoked or suspended? If you answered 'Yes' to either 34a or b, please explain using an attached statement		
35	Does the organization certify that it has complied with the applicable requirements of sections 4 01 through 4 05 of Rev Proc 75-50, 1975-2 C B 587, covering racial nondiscrimination? If 'No,' attach an explanation		

Part VI-A Lobbying Expenditures by Electing Public Charities (See instructions)
 (To be completed ONLY by an eligible organization that filed Form 5768)

N/A

Check **a** if the organization belongs to an affiliated group Check **b** if you checked 'a' and 'limited control' provisions apply

Limits on Lobbying Expenditures

(The term 'expenditures' means amounts paid or incurred.)

	(a) Affiliated group totals	(b) To be completed for ALL electing organizations
36 Total lobbying expenditures to influence public opinion (grassroots lobbying)	36	
37 Total lobbying expenditures to influence a legislative body (direct lobbying)	37	
38 Total lobbying expenditures (add lines 36 and 37)	38	
39 Other exempt purpose expenditures	39	
40 Total exempt purpose expenditures (add lines 38 and 39)	40	
41 Lobbying nontaxable amount. Enter the amount from the following table –		
If the amount on line 40 is –		
Not over \$500,000		
Over \$500,000 but not over \$1,000,000		
Over \$1,000,000 but not over \$1,500,000		
Over \$1,500,000 but not over \$17,000,000		
Over \$17,000,000		
The lobbying nontaxable amount is –		
20% of the amount on line 40		
\$100,000 plus 15% of the excess over \$500,000		
\$175,000 plus 10% of the excess over \$1,000,000	41	
\$225,000 plus 5% of the excess over \$1,500,000		
\$1,000,000		
42 Grassroots nontaxable amount (enter 25% of line 41)	42	
43 Subtract line 42 from line 36 Enter -0- if line 42 is more than line 36 .	43	
44 Subtract line 41 from line 38 Enter -0- if line 41 is more than line 38	44	
Caution: If there is an amount on either line 43 or line 44, you must file Form 4720		

4 -Year Averaging Period Under Section 501(h)

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below
 See the instructions for lines 45 through 50)

Calendar year (or fiscal year beginning in) ▶	Lobbying Expenditures During 4 -Year Averaging Period				
	(a) 2005	(b) 2004	(c) 2003	(d) 2002	(e) Total
45 Lobbying nontaxable amount					
46 Lobbying ceiling amount (150% of line 45(e))					
47 Total lobbying expenditures					
48 Grassroots non-taxable amount					
49 Grassroots ceiling amount (150% of line 48(e))					
50 Grassroots lobbying expenditures					

Part VI-B Lobbying Activity by Nonelecting Public Charities
 (For reporting only by organizations that did not complete Part VI-A) (See instructions)

During the year, did the organization attempt to influence national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:

- a Volunteers
- b Paid staff or management (Include compensation in expenses reported on lines c through h.)
- c Media advertisements
- d Mailings to members, legislators, or the public
- e Publications, or published or broadcast statements
- f Grants to other organizations for lobbying purposes
- g Direct contact with legislators, their staffs, government officials, or a legislative body
- h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any other means
- i Total lobbying expenditures (add lines c through h.)

Yes	No	Amount
X		
	X	
	X	
	X	
	X	
	X	
X		491.
	X	
		491.

If 'Yes' to any of the above, also attach a statement giving a detailed description of the lobbying activities **SEE ATTACHED**

Form 990, Page 2, Part II, Line 43

Other Expenses Stmt

	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
Other expenses not covered above (itemize):				
Board & staff development	6,085.	6,085.	0.	0.
Fundraising expenses	3,648.	0.	0.	3,648.
Total	9,733.	6,085.	0.	3,648.

Page 3, Part III - STATEMENT OF PROGRAM SERVICE ACCOMPLISHMENTS

Educational Resources

Quarterly newsletter with personal stories, articles by medical professionals, event and resource information \$ 37,180

Patient Family Conference

In alternating years, a National Patient Education Conference in conjunction with the Mayo Clinic, Rochester, MN., or several Regional Conferences are held. Conferences are used for patient and family education and support, to recruit and train local volunteers, and to review emerging issues in Adult Congenital Heart Disease. \$ 30,196

Outreach & Advocacy

ACHA is a national media resource on adult congenital heart disease, raising public awareness about many issues including the urgent needs for appropriate care, research and initiatives and increased funding. \$ 15,524

Organizational Development

ACHA is increasing its organizational capacity by increasing staff, opening its first office and through its programs. \$ 9,305

ACHA 2005 Activity Report

Educational Resource Programs:

ACHA Website

ACHA's website continued to offer information, resources, and support to thousand of congenital heart defect survivors and those who care for them. The ACHA on-line discussion board grew doubled in size and continued to offer a lifeline of hope and support throughout the community.

***Heart Matters* Newsletter**

Since 1998, ACHA's newsletter has brought the congenital heart community cutting-edge medical information, heart warming personal stories, and a variety of other resources to enhance the well-being of the heart defect community. 2005 brought a new name, *Heart Matters*, and a new expanded format. Over that calendar year, circulation more than doubled, and by year-end, in addition top reaching all ACHA members, *Heart Matters* was distributed at over 200 cardiology clinics.

Personal Health Passport

With generous support from the American College of Cardiology (ACC), ACHA produced our first Personal Health Passport, designed to both educate patients as to their health care needs and serve as a life-saving resource in a medical emergency. In 2005 over 10,000 ACHA Health Passports were requested by pediatric and adult congenital heart clinics throughout the country. ACHA also began developing an electronic ACHD health passport.

National ACHD Clinic Survey

In collaboration with the International Society of Adult Congenital Cardiac Disease (ISACCD) and with funding from Hitachi Global Storage Technologies and the Hitachi Foundation, ACHA initiated the first national survey of ACHD clinics. Surveys were completed by over 50 self-identified adult congenital heart clinics in the United States, Canada, and the United Kingdom, and ACHA began compiling a national database offering contacts and objective information to help patients and families make more informed decisions about their care.

Internet Toolkit Initiative

Thanks to funding support from the Medtronic Patient Link Program, ACHA began a major revision of its website to enhance patient access to the "tools" they need to maximize their health and well-being. Specific new tools in development included a secure on-line version of the Personal Health Passport, a searchable ACHD clinic database, and an improved on-line patient resource room.

Outreach and Advocacy Initiatives:

Outreach and Advocacy for Public Awareness

ACHA continued to be a national media resource on adult congenital heart disease. In the fall of 2004, ACHA's Board of Directors identified raising public awareness about the many CHD survivors currently "lost" to appropriate care as a central goal. 2005 brought a number of major media pieces targeting this issue featuring ACHA staff, board, and medical advisory board.

Outreach and Advocacy for Appropriate Care

Throughout the year, ACHA educated cardiologists and other health care professionals about the unmet needs of congenital heart defect survivors in a variety of venues such as the Pediatric Cardiac Intensive Care Society, the 15th Annual International Symposium on Congenital Heart Disease in the Adult, and the ISACCD. For the first time, ACHA exhibited at the AHA Scientific Sessions and provided over 10,000 attending cardiac professionals with resources and information to help them meet the needs of their patients with CHD. In March, at the American College of Cardiology Scientific Session 2005, ACHA addressed attending health professionals about the slow rate of progress in providing appropriate care for this country's adult congenital heart survivors, and the severe endangerment of our community. This session grew into the ACC Working Group on Adult Congenital Heart Disease, which worked together throughout the year to move forward initiatives to support adults with congenital heart defects.

Outreach and Advocacy for ACHD Research

In the fall of 2004, ACHA was invited to participate in the first-ever National Heart, Lung, and Blood Institute (NHLBI) Working Group on Research Needs in Adult Congenital Heart Disease. The Working Group worked throughout the spring of 2005 to develop recommendations on needed research and initiatives, identifying three areas of crucial need: outreach initiatives to reach the many heart defect survivors currently "lost" to appropriate care, the initiation of multi-institutional studies in ACHD, and the development of a national ACHD registry. Based on this report, ACHA began organizing its first National ACHD Lobby Day to promote Congressional awareness of ACHD in the hopes for more federal funding for research in ACHD and a national ACHD registry. Through the venue of the ACC working group, ACHA also developed strategies for initiating multi-center ACHD research focused on the investigating the provision of care to heart defect survivors.

Regional Patient-Family Conferences

A major initiative in 2005 was the execution of regional patient-family conferences targeted to providing congenital heart patients and their families with the best in ACHD health information. Events were held in Teaneck, New Jersey; Kissimmee, Florida; and Manhattan Beach, California; and were co-sponsored by Columbia University Medical Center; The University of Florida, Gainesville; and the Ahmanson ACHD Clinic at UCLA. These events featured speakers from 22 different medical institutions in 11 different states, and brought together approximately 250 patients and family members for peer support and education by regional health experts. Attendee feedback was excellent, and over 98% of participants stated that they would attend another ACHD conference.

Organizational Development

- Recognizing that growing our impact would require higher organizational capacity, in 2004 ACHA identified expanding beyond its all-volunteer beginnings as a primary objective. A first step, in spring of 2004, was hiring an association management company to oversee ACHA functions. The next step, undertaken in spring of 2005, was hiring our first paid staff and opening our first office. In June of 2005, ACHA opened our office at 6757 Greene Street in Philadelphia, and created its first, part-time, staff position. In September of 2005, ACHA President Amy Verstappen stepped off the Board to become ACHA's first paid President/CEO ; this became a salaried position in January of 2006.

With generous support from the Medtronic Foundation's Patient Link Program, the ACHA board and staff participated in a number of training programs targeted to help improve ACHA's professionalism and impact, and in October of 2005 the ACHA Board convened from throughout the country for ACHA's third strategic retreat.

**Adult Congenital Heart Association
Offices and Directors
2005–2006**

Officers

Board Chairman

Jim Wong
3754 Deedham Drive
San Jose, CA 95148

Treasurer

Jeff Driver
3010 Hennepin Avenue S, #290
Minneapolis, MN 55408

Vice-Chair

Paul Miller
1146 Huntsman Lane
Memphis, TN 38120

Secretary

Linda Miller
17 Eaton Road
Framingham, MA 01701

Board of Directors

Gwendolyn Elfers
132A Bruno Ave
Daly City CA 94014

Sara Minelli
9401 Odyssey Court
Burke VA 22015

Rudy Wilson Galdonik
PO Box 528
East Greenwich RI 02818

Loretta Ninivaggi
18 Princeton Dr
Howell NJ 07731

Kevin Gordon
5560 Bristol Lane
Minnetonka MN 55343

Anthony Pugliese
107 North 9th St
Jeanette PA 15644

Lisa Kirkland
2129 Northview Lane NE
Rochester MN 55906

George Warren
1458 So Humbolt St
Denver CO 80210

Karen Matson
2207 SE 2nd Place
Renton WA 98056

Jim Wong
3754 Deedham Dr.
San Jose, CA 95148

2005080-751

PENNSYLVANIA DEPARTMENT OF STATE
CORPORATION BUREAU

Application for Certificate of Authority
(15 Pa.C.S.)

Entity Number
3326366

- Foreign Business Corporation (§ 4124)
- Foreign Nonprofit Corporation (§ 6124)

Name
Adult Congenital Heart Association

Address
6757 Greene Street

City State Zip Code
Philadelphia PA 19119

Document will be returned to the name and address you enter to the left.



Fee: \$250

Filed in the Department of State on AUG 08 2005

Perth C. Conte's

Secretary of the Commonwealth

09

In compliance with the requirements of the applicable provisions of 15 Pa.C.S. (relating to corporations and unincorporated associations), the undersigned, hereby states that:

1 The name of the corporation is:
Adult Congenital Heart Association, Inc.

2. Complete only when the corporation must adopt a corporate designator for use in Pennsylvania.
The name which the corporation adopts for use in this Commonwealth is:

3. If the name set forth in paragraph 1 or 2 is not available for use in this Commonwealth, complete the following.
The fictitious name which the corporation adopts for use in transacting business in this Commonwealth is.

The corporation shall do business in Pennsylvania only under such fictitious name pursuant to the attached resolution of the board of directors under the applicable provisions of 15 Pa.C.S. (relating to corporations and unincorporated associations) and the attached form DSCB:54-311 (Application for Registration of Fictitious Name).

4 The name of the jurisdiction under the laws of which the corporation is incorporated is: MA

5. The address of its principal office under the laws of the jurisdiction in which it is incorporated is
273 Perham Street, West Roxbury MA 02132

Number and street City State Zip

DEPT OF STATE

AUG 9 8 2005

2005083-752

DSCB-15-4124/6124-2

6 The (a) address of this corporation's proposed registered office in this Commonwealth or (b) name of its commercial registered office provider and the county of venue is:

(a) Number and street	City	State	Zip	County
6757 Greene Street	Philadelphia	PA	19119	

(b) Name of Commercial Registered Office Provider _____ County _____
c/o. _____

7. Check one of the following:

Business Corporation: The corporation is a corporation incorporated for a purpose or purposes involving pecuniary profit, incidental or otherwise.

Nonprofit Corporation: The corporation is a corporation incorporated for a purpose or purposes not involving pecuniary profit, incidental or otherwise.

IN TESTIMONY WHEREOF, the undersigned corporation has caused this Application for Certificate of Authority to be signed by a duly authorized officer thereof this 8th day of July, 2005

Adult Congenital Heart Association, Inc.

 Name of Corporation

G. J. [Signature]

 Signature

Treasurer

 Title

SCHEDULE A, PAGE 2, PART III, LINE 1
SCHEDULE A, PAGE 5, PART VI-B

DESCRIPTION OF LOBBYING ACTIVITIES

The Adult Congenital Heart Association participated in a National ACHD Lobby Day in Washington, DC in 2006, where its delegation was able to sit down in a face to face meeting with congressmen and discuss the issues of concern.

The amount of expenses listed represents the cost for its delegation to travel to Washington, DC.



Application for Extension of Time to File an Exempt Organization Return

Department of the Treasury
Internal Revenue Service

▶ File a separate application for each return

- If you are filing for an **Automatic 3-Month Extension**, complete only **Part I** and check this box
- If you are filing for an **Additional (not automatic) 3-Month Extension**, complete only **Part II** (on page 2 of this form)

Do not complete Part II unless you have already been granted an automatic 3-month extension on a previously filed Form 8868

Part I Automatic 3-Month Extension of Time — Only submit original (no copies needed)

Form 990-T corporations requesting an automatic 6-month extension — check this box and complete Part I only

All other corporations (including Form 990-C filers) must use Form 7004 to request an extension of time to file income tax returns. Partnerships, REMICs and trusts must use Form 8736 to request an extension of time to file Form 1065, 1066, or 1041

Electronic Filing (e-file). Form 8868 can be filed electronically if you want a 3-month automatic extension of time to file one of the returns noted below (6-months for corporate Form 990-T filers). However, you cannot file it electronically if you want the additional (not automatic) 3-month extension, instead you must submit the fully completed signed page 2 (Part II) of Form 8868. For more details on the electronic filing of this form, visit www.irs.gov/efile.

Type or print File by the due date for filing your return. See instructions	Name of Exempt Organization ADULT CONGENITAL HEART ASSOCIATION	Employer identification number 04-3447959
	Number, street, and room or suite number. If a P O box, see instructions 6757 GREENE ST, #3RD FLOOR	
	City, town or post office. For a foreign address, see instructions PHILADELPHIA	state ZIP code PA 19119

Check type of return to be filed (file a separate application for each return):

<input checked="" type="checkbox"/> Form 990	<input type="checkbox"/> Form 990-T (corporation)	<input type="checkbox"/> Form 4720
<input type="checkbox"/> Form 990-BL	<input type="checkbox"/> Form 990-T (section 401(a) or 408(a) trust)	<input type="checkbox"/> Form 5227
<input type="checkbox"/> Form 990-EZ	<input type="checkbox"/> Form 990-T (trust other than above)	<input type="checkbox"/> Form 6069
<input type="checkbox"/> Form 990-PF	<input type="checkbox"/> Form 1041-A	<input type="checkbox"/> Form 8870

- The books are in the care of **Organization** -----

Telephone No ▶ (215) 849-1260 FAX No ▶ -----

- If the organization does **not** have an office or place of business in the United States, check this box
- If this is for a **Group Return**, enter the organization's four digit Group Exemption Number (GEN) _____. If this is for the **whole** group, check this box . If it is for part of the group, check this box and attach a list with the names and EINs of all members the extension will cover.

1 I request an automatic 3-month (6-months for a **Form 990-T corporation**) extension of time until **Aug 15**, 20 **06**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:

- ▶ calendar year 20 **05** or
- ▶ tax year beginning _____, 20____, and ending _____, 20____.

2 If this tax year is for less than 12 months, check reason: Initial return Final return Change in accounting period

3a If this application is for Form 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions. \$ _____ 0.

b If this application is for Form 990-PF or 990-T, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. \$ _____ 0.

c **Balance Due.** Subtract line 3b from line 3a. Include your payment with this form, or, if required, deposit with FTD coupon or, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions. \$ _____ 0.

Caution. If you are going to make an electronic fund withdrawal with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.