

**Return of Organization Exempt From Income Tax**

**2011**

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.

**A For the 2011 calendar year, or tax year beginning** , 2011, and ending

**B** Check if applicable:  
 Address change  
 Name change  
 Initial return  
 Terminated  
 Amended return  
 Application pending

**C Name of organization** **ADULT CONGENITAL HEART ASSOCIATION**  
 Doing Business As  
 Number and street (or P.O. box if mail is not delivered to street addr) Room/suite  
**6757 GREENE ST SUITE 335**  
 City, town or country State ZIP code + 4  
**PHILADELPHIA PA 19119**

**D Employer Identification Number**  
**04-3447959**

**E Telephone number**  
**(215) 849-1260**

**F Name and address of principal officer**  
**Amy Verstappen 6757 Greene St #335 Phila PA 19119**

**G Gross receipts** \$ **1,346,342.**

**H(a)** Is this a group return for affiliates?  Yes  No  
**H(b)** Are all affiliates included?  Yes  No  
 If 'No,' attach a list (see instructions)

**I Tax-exempt status**  501(c)(3)  501(c) ( ) (insert no)  4947(a)(1) or  527

**J Website:** **www.achaheart.org**

**K Form of organization**  Corporation  Trust  Association  Other

**L Year of Formation** **1998**

**M State of legal domicile** **PA**

**H(c) Group exemption number**

**Part I Summary**

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: <b>The Adult Congenital Heart Association (ACHA) is a nonprofit organization that seeks to improve the quality of life and extend the lives of adults with congenital heart defects. Through education, outreach, advocacy and promotion of research, ACHA serves and supports the more than one million adults with congenital heart defects, their families and medical community.</b>	
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets	
	3 Number of voting members of the governing body (Part VI, line 1a)	3 16
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4 16
	5 Total number of individuals employed in calendar year 2011 (Part V, line 2a)	5 10
	6 Total number of volunteers (estimate if necessary)	6 275
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a 0.
7b Net unrelated business taxable income from Form 990-T, line 34	7b 0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year 647,946. Current Year 1,225,897.
	9 Program service revenue (Part VIII, line 2g)	11,553. 119,098.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	7.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	439. 1,347.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	659,945. 1,346,342.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	
	14 Benefits paid to or for members (Part IX, column (A), line 4)	
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	260,781. 463,821.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	
	b Total fundraising expenses (Part IX, column (D), line 25) <b>105,481.</b>	
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	360,702. 629,306.	
18 Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	621,483. 1,093,127.	
19 Revenue less expenses. Subtract line 18 from line 12	38,462. 253,215.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 269,695. End of Year 508,144.
	21 Total liabilities (Part X, line 26)	41,788. 27,022.
	22 Net assets or fund balances. Subtract line 21 from line 20	227,907. 481,122.

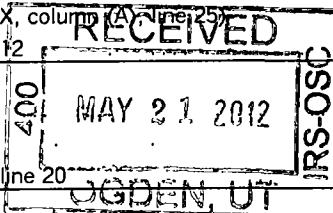
**Part II Signature Block**

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: *Amy Verstappen* Date: **5/14/12**  
 Type or print name and title: **Amy Verstappen**

**Paid Preparer Use Only**  
 Print/Type preparer's name: **Joseph P. Leonard** Preparer's signature: *Joseph P. Leonard CPA* Date: **05/14/12** Check  if self-employed PTIN: **P00229620**  
 Firm's name: **SNYDER, DALEZ & COMPANY**  
 Firm's address: **1617 JOHN F. KENNEDY BLVD., SUITE 670 PHILADELPHIA PA 19103** Firm's EIN: **23-1436393** Phone no: **(215) 563-6141**

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



617 19

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response to any question in this Part III

X

1 Briefly describe the organization's mission:

The Adult Congenital Heart Association (ACHA)

is a nonprofit organization that seeks to improve the quality of life and extend the lives of adults with congenital
See Form 990, Page 2, Part III, Line 1 (continued)

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 X

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 X

If 'Yes,' describe these changes on Schedule O

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured 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 \$ 613,388. including grants of \$ 0.) (Revenue \$ 120,445.)

Educational & Outreach :

See ACHA Program 2011 attachment to Schedule O

4b (Code: ) (Expenses \$ 51,292. including grants of \$ 0.) (Revenue \$ 0.)

Advocacy :

See ACHA Program 2011 attachment to Schedule O

4c (Code: ) (Expenses \$ 175,123. including grants of \$ 0.) (Revenue \$ 0.)

Research

See ACHA Program 2011 attachment to Schedule O

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

(Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses 839,803.

**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 (see instructions)?	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 <b>Section 501(c)(3) organizations</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If 'Yes,' complete Schedule C, Part II	X	
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If 'Yes,' complete Schedule C, Part III	N/A	
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which 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, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If 'Yes,' complete Schedule D, Part V		X
11 If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings and equipment in Part X, line 10? If 'Yes,' complete Schedule D, Part VI		X
b Did the organization report an amount for investments— other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VII		X
c Did the organization report an amount for investments— program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VIII		X
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part IX		X
e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If 'Yes,' complete Schedule D, Part X		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI, XII, and XIII	X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? If 'Yes,' and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI, XII, and XIII is optional		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 United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If 'Yes,' complete Schedule F, Parts I and IV		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, Parts II and IV		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, Parts III and IV		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If 'Yes,' complete Schedule G, Part I (see instructions)		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If 'Yes,' complete Schedule G, Part II		X
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If 'Yes,' complete Schedule G, Part III		X
20 a Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule H		X
b If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?	N/A	

**Part IV Checklist of Required Schedules (continued)**

	Yes	No
21 Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If 'Yes,' complete Schedule I, Parts I and II</i>		X
22 Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If 'Yes,' complete Schedule I, Parts I and III</i>		X
23 Did the organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If 'Yes,' complete Schedule J</i>		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, and that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25</i>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	N/A	
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?	N/A	
d Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	N/A	
25a <b>Section 501(c)(3) and 501(c)(4) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If 'Yes,' complete Schedule L, Part I</i>		X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If 'Yes,' complete Schedule L, Part I</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? <i>If 'Yes,' complete Schedule L, Part II</i>		X
27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If 'Yes,' complete Schedule L, Part III</i>		X
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV</i>		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV</i>		X
c An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <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
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
b Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If 'Yes,' complete Schedule R, Part V, line 2</i>		X
36 <b>Section 501(c)(3) organizations.</b> 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
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O	X	

**Part V** Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response to any question in this Part V

		Yes	No
1 a	6	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
1 b	0	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		1 c	<input checked="" type="checkbox"/>
2 a	10	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. (see instructions)		2 b	<input checked="" type="checkbox"/>
3 a Did the organization have unrelated business gross income of \$1,000 or more during the year?		3 a	<input checked="" type="checkbox"/>
b If 'Yes,' has it filed a Form 990-T for this year? If 'No,' provide an explanation in Schedule O.		3 b	N/A
4 a 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)?		4 a	<input checked="" type="checkbox"/>
b If 'Yes,' enter the name of the foreign country: See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts			<input checked="" type="checkbox"/>
5 a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		5 a	<input checked="" type="checkbox"/>
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		5 b	<input checked="" type="checkbox"/>
c If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?		5 c	N/A
6 a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible?		6 a	<input checked="" type="checkbox"/>
b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		6 b	N/A
<b>7 Organizations that may receive deductible contributions under section 170(c).</b>			
a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		7 a	<input checked="" type="checkbox"/>
b If 'Yes,' did the organization notify the donor of the value of the goods or services provided?		7 b	N/A
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		7 c	<input checked="" type="checkbox"/>
d If 'Yes,' indicate the number of Forms 8282 filed during the year		7 d	N/A
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		7 e	<input checked="" type="checkbox"/>
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		7 f	<input checked="" type="checkbox"/>
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		7 g	N/A
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		7 h	N/A
8 <b>Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations.</b> Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?		8	<input checked="" type="checkbox"/>
<b>9 Sponsoring organizations maintaining donor advised funds.</b>			
a Did the organization make any taxable distributions under section 4966?		9 a	<input checked="" type="checkbox"/>
b Did the organization make a distribution to a donor, donor advisor, or related person?		9 b	<input checked="" type="checkbox"/>
<b>10 Section 501(c)(7) organizations.</b> Enter:			
a Initiation fees and capital contributions included on Part VIII, line 12		10 a	N/A
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		10 b	N/A
<b>11 Section 501(c)(12) organizations.</b> Enter:			
a Gross income from members or shareholders		11 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)		11 b	N/A
12 a <b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?		12 a	N/A
b If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year		12 b	N/A
<b>13 Section 501(c)(29) qualified nonprofit health insurance issuers.</b>			
a Is the organization licensed to issue qualified health plans in more than one state? <b>Note.</b> See the instructions for additional information the organization must report on Schedule O		13 a	N/A
b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans		13 b	N/A
c Enter the amount of reserves on hand		13 c	N/A
14 a Did the organization receive any payments for indoor tanning services during the tax year?		14 a	<input checked="" type="checkbox"/>
b If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O		14 b	N/A

**Part VI Governance, Management and Disclosure** For each 'Yes' response to lines 2 through 7b below, and for a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

Check if Schedule O contains a response to any question in this Part VI...

**Section A. Governing Body and Management**

	1a	1b	2	3	4	5	6	7a	7b	8a	8b	9	Yes	No
1 a Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O	16													
b Enter the number of voting members included in line 1a, above, who are independent		16												
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee or key employee?														X
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?				X										
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?														X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?														X
6 Did the organization have members or stockholders?														X
7 a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?														X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or other persons other than the governing body?														X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:														
a The governing body?				X										
b Each committee with authority to act on behalf of the governing body?				N/A										
9 Is there any officer, director or trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If 'Yes,' provide the names and addresses in Schedule O														X

**Section B. Policies** (This Section B requests information about policies not required by the Internal Revenue Code.)

	10a	10b	11a	11b	12a	12b	12c	13	14	15a	15b	16a	16b	Yes	No
10 a Did the organization have local chapters, branches, or affiliates?															X
b If 'Yes,' did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?		N/A													
11 a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?			X												
b Describe in Schedule O the process, if any, used by the organization to review this Form 990.															
12 a Did the organization have a written conflict of interest policy? If 'No,' go to line 13			X												
b Were officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?			X												
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If 'Yes,' describe in Schedule O how this is done			X												
13 Did the organization have a written whistleblower policy?			X												
14 Did the organization have a written document retention and destruction policy?			X												
15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?															
a The organization's CEO, Executive Director, or top management official			X												
b Other officers of key employees of the organization If 'Yes' to line 15a or 15b, describe the process in Schedule O. (See instructions.)			X												
16 a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?															X
b If 'Yes,' did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?															N/A

**Section C. Disclosure**

- 17 List the states with which a copy of this Form 990 is required to be filed ► Pennsylvania
- 18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.  
 Own website     Another's website     Upon request
- 19 Describe in Schedule O whether (and if so, how) the organization makes its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization:  
 ► Management    6757 Greene St., Suite 335, Phila    PA 19119    (215) 849-1260

**Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**

Check if Schedule O contains a response to any question in this Part VII

**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of 'key employee.'
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee

(A) Name and title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) <u>Peggy Powers</u> Board Chair (Sch.O)	3.00	X		X				0.	0.	0.
(2) <u>Barry R. Meil</u> Board Vice-Chair (Sch.O)	3.00	X		X				0.	0.	0.
(3) <u>Anne Gammon</u> Board Secretary (Aug-Dec)	3.00	X		X				0.	0.	0.
(4) <u>Kevin Gordon</u> Board Secretary (Jan-July) (Sch.O)	3.00	X		X				0.	0.	0.
(5) <u>Heather Abbott</u> Board Treasurer	3.00	X		X				0.	0.	0.
(6) <u>Brian Altman</u> Board Member (Sch.O)	1.00	X						0.	0.	0.
(7) <u>Jerry Boegler</u> Board Member	1.00	X						0.	0.	0.
(8) <u>Stephen Brabeck</u> Board Member	1.00	X						0.	0.	0.
(9) <u>Denise Curcio</u> Board Member	1.00	X						0.	0.	0.
(10) <u>Curt Daniels</u> Board Member	1.00	X						0.	0.	0.
(11) <u>Bill Davidson</u> Board Member (Sch.O)	1.00	X						0.	0.	0.
(12) <u>Kay Deeney</u> Board Member	1.00	X						0.	0.	0.
(13) <u>Elyse Foster</u> Board Member	1.00	X						0.	0.	0.
(14) <u>Jenne Hickey</u> Board Member	1.00	X						0.	0.	0.

**Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (cont)**

(A) Name and title	(B) Average hours per week (describe hours for related organizations in Sch O)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(15) <u>Cindy Huie</u> Board Member	1.00	X						0.	0.	0.
(16) <u>Michael Landzberg</u> Board Member	1.00	X						0.	0.	0.
(17) <u>Martha Pauly</u> Board Member	1.00	X						0.	0.	0.
(18) <u>Marion Wachtenheim</u> Board Member	1.00	X						0.	0.	0.
(19) <u>George Warren</u> Board Member	1.00	X						0.	0.	0.
(20) <u>David Watkins</u> Board Member (Sch.O)	1.00	X						0.	0.	0.
(21) <u>Amy Verstappen</u> President/CEO	40.00			X	X			93,445.	0.	6,307.
(22) _____										
(23) _____										
(24) _____										
(25) _____										
<b>1 b Sub-total</b>								<b>93,445.</b>	<b>0.</b>	<b>6,307.</b>
<b>c Total from continuation sheets to Part VII, Section A</b>										
<b>d Total (add lines 1b and 1c)</b>								<b>93,445.</b>	<b>0.</b>	<b>6,307.</b>

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization **0**

	Yes	No
3 Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? If 'Yes,' complete Schedule J for such individual		X
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If 'Yes' complete Schedule J for such individual		X
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If 'Yes,' complete Schedule J for such person		X

**Section B. Independent Contractors**

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization **0**

**Part VIII Statement of Revenue**

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514		
<b>CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS</b>	<b>1 a</b> Federated campaigns	<b>1 a</b>					
	<b>b</b> Membership dues	<b>1 b</b> 16,183.					
	<b>c</b> Fundraising events	<b>1 c</b>					
	<b>d</b> Related organizations	<b>1 d</b>					
	<b>e</b> Government grants (contributions)	<b>1 e</b> 105,070.					
	<b>f</b> All other contributions, gifts, grants, and similar amounts not included above	<b>1 f</b> 1,104,644.					
	<b>g</b> Noncash contributions included in lns 1a-1f	\$ 9,134.					
	<b>h Total.</b> Add lines 1a-1f		<b>1,225,897.</b>				
<b>PROGRAM SERVICE REVENUE</b>	<b>2 a</b> <u>Conferences</u>		<b>624100</b>	<b>117,320.</b>	<b>117,320.</b>	<b>0.</b>	<b>0.</b>
	<b>b</b> <u>Publications</u>		<b>624100</b>	<b>1,778.</b>	<b>1,778.</b>	<b>0.</b>	<b>0.</b>
	<b>c</b> -----						
	<b>d</b> -----						
	<b>e</b> -----						
	<b>f</b> All other program service revenue						
	<b>g Total.</b> Add lines 2a-2f			<b>119,098.</b>			
<b>OTHER REVENUE</b>	<b>3</b> Investment income (including dividends, interest and other similar amounts)						
	<b>4</b> Income from investment of tax-exempt bond proceeds						
	<b>5</b> Royalties						
	<b>6 a</b> Gross rents	(i) Real	(ii) Personal				
		<b>b</b> Less: rental expenses					
		<b>c</b> Rental income or (loss)					
		<b>d</b> Net rental income or (loss)					
	<b>7 a</b> Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
		<b>b</b> Less: cost or other basis and sales expenses					
		<b>c</b> Gain or (loss)					
		<b>d</b> Net gain or (loss)					
	<b>8 a</b> Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c) See Part IV, line 18	<b>a</b>					
		<b>b</b> Less: direct expenses	<b>b</b>				
		<b>c</b> Net income or (loss) from fundraising events					
	<b>9 a</b> Gross income from gaming activities See Part IV, line 19	<b>a</b>					
		<b>b</b> Less: direct expenses	<b>b</b>				
		<b>c</b> Net income or (loss) from gaming activities					
<b>10 a</b> Gross sales of inventory, less returns and allowances	<b>a</b>						
	<b>b</b> Less: cost of goods sold	<b>b</b>					
	<b>c</b> Net income or (loss) from sales of inventory						
<b>Miscellaneous Revenue</b>		<b>Business Code</b>					
<b>11 a</b> <u>Merchandise</u>	<b>624100</b>	<b>1,347.</b>	<b>1,347.</b>	<b>0.</b>	<b>0.</b>		
	<b>b</b> -----						
	<b>c</b> -----						
	<b>d</b> All other revenue						
<b>e Total.</b> Add lines 11a-11d			<b>1,347.</b>				
<b>12 Total revenue.</b> See instructions			<b>1,346,342.</b>	<b>120,445.</b>	<b>0.</b>	<b>0.</b>	

**Part IX: Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns.

All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D)

Check if Schedule O contains a response to any question in this Part IX

<i>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</i>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the United States See Part IV, line 21				
2 Grants and other assistance to individuals in the United States See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees				
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	393,171.	254,230.	76,924.	62,017.
8 Pension plan accruals and contributions (include section 401(k) and section 403(b) employer contributions)				
9 Other employee benefits	33,934.	21,859.	6,947.	5,128.
10 Payroll taxes	36,716.	24,308.	6,821.	5,587.
11 Fees for services (non-employees).				
a Management				
b Legal				
c Accounting	21,510.	11,191.	7,977.	2,342.
d Lobbying				
e Professional fundraising services See Part IV, line 17				
f Investment management fees				
g Other	103,563.	87,058.	15,198.	1,307.
12 Advertising and promotion				
13 Office expenses	120,582.	92,499.	12,205.	15,878.
14 Information technology	91,377.	80,085.	5,401.	5,891.
15 Royalties				
16 Occupancy	17,650.	11,727.	3,226.	2,697.
17 Travel	69,384.	65,722.	2,125.	1,537.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest	32.	0.	32.	0.
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	2,917.	1,591.	706.	620.
23 Insurance	3,771.	2,471.	703.	597.
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <b>Other program expenses</b>	191,926.	183,959.	6,412.	1,555.
b <b>Board &amp; staff development</b>	6,594.	3,103.	3,166.	325.
c				
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	1,093,127.	839,803.	147,843.	105,481.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

**Part X Balance Sheet**

		(A) Beginning of year		(B) End of year
ASSETS	1 Cash – non-interest-bearing	219,116.	1	129,637.
	2 Savings and temporary cash investments		2	12,134.
	3 Pledges and grants receivable, net	30,500.	3	289,707.
	4 Accounts receivable, net	11,828.	4	57,225.
	5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 Receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	3,703.	9	8,092.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 15,403.		
	b Less: accumulated depreciation	10b 4,054.	4,548.	10c 11,349.
	11 Investments – publicly traded securities		11	
	12 Investments – other securities See Part IV, line 11		12	
	13 Investments – program-related See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	
16 <b>Total assets.</b> Add lines 1 through 15 (must equal line 34)		269,695.	16	508,144.
LIABILITIES	17 Accounts payable and accrued expenses	41,788.	17	27,022.
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability Complete Part IV of Schedule D		21	
	22 Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		25	
	26 <b>Total liabilities.</b> Add lines 17 through 25		41,788.	26
NET ASSETS OR FUND BALANCES	<b>Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 27 through 29 and lines 33 and 34.</b>			
	27 Unrestricted net assets	18,111.	27	116,150.
	28 Temporarily restricted net assets	209,796.	28	364,972.
	29 Permanently restricted net assets		29	
	<b>Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 30 through 34.</b>			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	227,907.	33	481,122.
34 Total liabilities and net assets/fund balances	269,695.	34	508,144.	

**Part XI Reconciliation of Net Assets**

Check if Schedule O contains a response to any question in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1,346,342.
2	Total expenses (must equal Part IX, column (A), line 25)	1,093,127.
3	Revenue less expenses. Subtract line 2 from line 1	253,215.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	227,907.
5	Other changes in net assets or fund balances (explain in Schedule O)	
6	Net assets or fund balances at end of year. Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	481,122.

**Part XII Financial Statements and Reporting**

Check if Schedule O contains a response to any question in this Part XII

- 1 Accounting method used to prepare the Form 990:  Cash  Accrual  Other \_\_\_\_\_  
 If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O
- 2a Were the organization's financial statements compiled or reviewed by an independent accountant?
- b Were the organization's financial statements audited by an independent accountant?
- c If 'Yes' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?  
 If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.
- d If 'Yes' to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a separate basis, consolidated basis, or both:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- 3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?
- b If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits

	Yes	No
2a		X
2b	X	
2c	X	
3a		X
3b	N/A	A

BAA

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No 1545-0047

**2011**

Open to Public Inspection

Name of the organization

**ADULT CONGENITAL HEART ASSOCIATION**

Employer identification number

**04 - 3447959**

**Part II Reason for Public Charity Status** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 11, check only one box.)

- 1  A church, convention of churches or association of churches described in **section 170(b)(1)(A)(i)**.
- 2  A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E.)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9  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 exempt 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)**. (Complete Part III.)
- 10  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 11  An organization organized and operated exclusively for the benefit of, to perform the functions of, or carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See **section 509(a)(3)**. Check the box that describes the type of supporting organization and complete lines 11e through 11h.
  - a  Type I
  - b  Type II
  - c  Type III – Functionally integrated
  - d  Type III – Other
- e  By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that is a Type I, Type II or Type III supporting organization, check this box
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

- (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
- (ii) A family member of a person described in (i) above?
- (iii) A 35% controlled entity of a person described in (i) or (ii) above?

	Yes	No
<b>11 g (i)</b>		
<b>11 g (ii)</b>		
<b>11 g (iii)</b>		

h Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in column (i) listed in your governing document?		(v) Did you notify the organization in column (i) of your support?		(vi) Is the organization in column (i) organized in the US?		(vii) Amount of support
			Yes	No	Yes	No	Yes	No	
(A)									
(B)									
(C)									
(D)									
(E)									
<b>Total</b>									

BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule A (Form 990 or 990-EZ) 2011

**Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)**

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants'.)	432,571.	346,187.	444,533.	647,946.	1,225,897.	3,097,134.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf.						
3 The value of services or facilities furnished by a governmental unit to the organization without charge.						
4 Total. Add lines 1 through 3.	432,571.	346,187.	444,533.	647,946.	1,225,897.	3,097,134.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f).						889,971.
6 Public support. Subtract line 5 from line 4.						2,207,163.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
7 Amounts from line 4.	432,571.	346,187.	444,533.	647,946.	1,225,897.	3,097,134.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	1,561.	777.	3.	7.	0.	2,348.
9 Net income from unrelated business activities, whether or not the business is regularly carried on.						
10 Other income. Do not include gain or loss from the sale of capital assets. (Explain in Part IV.)						
11 Total support. Add lines 7 through 10.						3,099,482.
12 Gross receipts from related activities, etc. (see instructions)					12	254,318.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here. ▶ <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

14 Public support percentage for 2011 (line 6, column (f) divided by line 11, column (f))	14	71.21 %
15 Public support percentage from 2010 Schedule A, Part II, line 14	15	72.17 %

16a 33-1/3% support test – 2011. If the organization did not check the box on line 13, and the line 14 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization. ▶

b 33-1/3% support test – 2010. If the organization did not check a box on line 13 or 16a, and line 15 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization. ▶

17a 10%-facts-and-circumstances test – 2011. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization. ▶

b 10%-facts-and-circumstances test – 2010. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization. ▶

18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions. ▶

**Part III Support Schedule for Organizations Described in Section 509(a)(2)** N/A

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

**Section A. Public Support**

Calendar year (or fiscal yr beginning in) ▶	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
<b>1</b> Gifts, grants, contributions and membership fees received. (Do not include any 'unusual grants'.)						
<b>2</b> Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge						
<b>6 Total.</b> Add lines 1 through 5						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons						
<b>b</b> Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
<b>c</b> Add lines 7a and 7b						
<b>8 Public support</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal yr beginning in) ▶	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
<b>9</b> Amounts from line 6 . . .						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
<b>c</b> Add lines 10a and 10b						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV) .						
<b>13 Total support.</b> (Add lns 9, 10c, 11, and 12)						
<b>14 First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2011 (line 8, column (f) divided by line 13, column (f))	15	%
<b>16</b> Public support percentage from 2010 Schedule A, Part III, line 15	16	%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for 2011 (line 10c, column (f) divided by line 13, column (f))	17	%
<b>18</b> Investment income percentage from 2010 Schedule A, Part III, line 17	18	%

- 19a 33-1/3% support tests – 2011.** If the organization did not check the box on line 14, and line 15 is more than 33-1/3%, and line 17 is not more than 33-1/3%, check this box and stop here. The organization qualifies as a publicly supported organization
- b 33-1/3% support tests – 2010.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33-1/3%, and line 18 is not more than 33-1/3%, check this box and stop here. The organization qualifies as a publicly supported organization
- 20 Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions



**SCHEDULE C**  
**(Form 990 or 990-EZ)**

**Political Campaign and Lobbying Activities**

OMB No 1545 0047

**2011**

Open to Public Inspection

For Organizations Exempt From Income Tax Under section 501(c) and section 527

▶ Complete if the organization is described below.

▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

Department of the Treasury  
Internal Revenue Service

If the organization answered 'Yes,' to Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below Do not complete Part I-B
- Section 527 organizations Complete Part I-A only

If the organization answered 'Yes,' to Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B Do not complete Part II-A

If the organization answered 'Yes,' to Form 990, Part IV, line 5 (Proxy Tax) or Form 990-EZ, Part V, line 35a (Proxy Tax), then

- Section 501(c)(4), (5), or (6) organizations: Complete Part III

Name of organization <b>ADULT CONGENITAL HEART ASSOCIATION</b>	Employer identification number <b>04-3447959</b>
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**Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.** N/A

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV
- 2 Political expenditures ▶ \$ \_\_\_\_\_
- 3 Volunteer hours

**Part I-B Complete if the organization is exempt under section 501(c)(3).** N/A

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ \$ \_\_\_\_\_
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$ \_\_\_\_\_
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? 
 Yes  No  
 Yes  No
- 4a Was a correction made?  
b If 'Yes,' describe in Part IV

**Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).** N/A

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ \$ \_\_\_\_\_
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ \$ \_\_\_\_\_
- 3 Total exempt function expenditures. Add lines 1 and 2 Enter here and on Form 1120-POL, line 17b ▶ \$ \_\_\_\_\_
- 4 Did the filing organization file Form 1120-POL for this year? 
 Yes  No
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments For each organization listed, enter the amount paid from the filing organization's funds Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC) If additional space is needed, provide information in Part IV.

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds If none, enter -0-	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization If none, enter -0-
(1)	-----			
(2)	-----			
(3)	-----			
(4)	-----			
(5)	-----			
(6)	-----			



**Part II-B** Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each 'Yes' response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?	X		
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	X		
c Media advertisements?		X	
d Mailings to members, legislators, or the public?		X	
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?	X		18,709.
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?		X	
j Total. Add lines 1c through 1i			18,709.
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
b If 'Yes,' enter the amount of any tax incurred under section 4912			
c If 'Yes,' enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

**Part III-A** Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

N/A

	Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?	3	

**Part III-B** Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered 'No' OR (b) Part III-A, line 3, is answered 'Yes.'

N/A

1 Dues, assessments and similar amounts from members	1
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).	
a Current year	2a
b Carryover from last year	2b
c Total	2c
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4
5 Taxable amount of lobbying and political expenditures (see instructions)	5

**Part IV** Supplemental Information

Complete this part to provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A; and Part II-B, line 1. Also, complete this part for any additional information.

Pt I-A Line 1 N/A

Pt II-B Line 1i N/A

Pt II-B, Line 1g The Adult Congenital Heart Association participated in a national congenital heart Lobby Day in Washington, DC in

**Part IV** Supplemental Information (continued)

2011, where its delegation was able to sit down in a face  
to face meeting with congressmen and discuss the issues  
delegation to travel to Washington,DC

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

ACHA also worked with others to support the 2010 passage of  
The Congenital Heart Futures Act for the United States  
to invest in more research and public health surveillance to improve the  
lifelong well-being of congenital heart patients. ACHA  
continues to work to ensure that the provisions outlined in this  
new law are adequately funded and appropriately implemented.

**SCHEDULE D  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

▶ Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.  
▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

**2011**

Open to Public Inspection

Name of the organization

Employer identification number

**ADULT CONGENITAL HEART ASSOCIATION**

**04-3447959**

**Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.** Complete if the organization answered 'Yes' to Form 990, Part IV, line 6. N/A

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate contributions to (during year)		
3 Aggregate grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		<input type="checkbox"/> Yes <input type="checkbox"/> No

**Part II Conservation Easements.** Complete if the organization answered 'Yes' to Form 990, Part IV, line 7. N/A

1 Purpose(s) of conservation easements held by the organization (check all that apply)

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> Preservation of open space	

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

Held at the End of the Tax Year	
2a	
2b	
2c	
2d	

a Total number of conservation easements

b Total acreage restricted by conservation easements

c Number of conservation easements on a certified historic structure included in (a)

d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ \_\_\_\_\_

4 Number of states where property subject to conservation easement is located ▶ \_\_\_\_\_

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?  Yes  No

6 Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year ▶ \_\_\_\_\_

7 Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶ \$ \_\_\_\_\_

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?  Yes  No

9 In Part XIV, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.** Complete if the organization answered 'Yes' to Form 990, Part IV, line 8. N/A

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenues included in Form 990, Part VIII, line 1 ▶ \$ \_\_\_\_\_

(ii) Assets included in Form 990, Part X ▶ \$ \_\_\_\_\_

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:

a Revenues included in Form 990, Part VIII, line 1 ▶ \$ \_\_\_\_\_

b Assets included in Form 990, Part X ▶ \$ \_\_\_\_\_

**Part III: Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets** (continued)

- 3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a  Public exhibition
  - b  Scholarly research
  - c  Preservation for future generations
  - d  Loan or exchange programs
  - e  Other \_\_\_\_\_
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIV
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?  Yes  No

**Part IV: Escrow and Custodial Arrangements.** Complete if the organization answered 'Yes' to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21. N/A

- 1 a Is the organization an agent, trustee, custodian, or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No
- b If 'Yes,' explain the arrangement in Part XIV and complete the following table:
- |                                 | Amount |
|---------------------------------|--------|
| c Beginning balance             | 1c     |
| d Additions during the year     | 1d     |
| e Distributions during the year | 1e     |
| f Ending balance                | 1f     |
- 2 a Did the organization include an amount on Form 990, Part X, line 21?  Yes  No
- b If 'Yes,' explain the arrangement in Part XIV

**Part V: Endowment Funds.** Complete if the organization answered 'Yes' to Form 990, Part IV, line 10. N/A

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1 a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment  \_\_\_\_\_ %
  - b Permanent endowment  \_\_\_\_\_ %
  - c Temporarily restricted endowment  \_\_\_\_\_ %
- The percentages in lines 2a, 2b, and 2c should equal 100%
- 3 a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |   | Yes    | No |
|---|--------|----|
| (i) unrelated organizations   | 3a(i)  |    |
| (ii) related organizations  | 3a(ii) |    |
| b If 'Yes' to 3a(ii), are the related organizations listed as required on Schedule R? | 3b     |    |
- 4 Describe in Part XIV the intended uses of the organization's endowment funds

**Part VI: Land, Buildings, and Equipment.** See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1 a Land				
b Buildings				
c Leasehold improvements				
d Equipment		15,403.	4,054.	11,349.
e Other				
<b>Total.</b> Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c))				<b>11,349.</b>

**Part VII** Investments – Other Securities. See Form 990, Part X, line 12.

N/A

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other		
(A) -----		
(B) -----		
(C) -----		
(D) -----		
(E) -----		
(F) -----		
(G) -----		
(H) -----		
(I) -----		
<b>Total.</b> (Column (b) must equal Form 990 Part X, column (B) line 12)		

**Part VIII** Investments – Program Related. See Form 990, Part X, line 13.

N/A

(a) Description of investment type	(b) Book value	(c) Method of valuation Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B) line 13)		

**Part IX** Other Assets. See Form 990, Part X, line 15.

N/A

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B), line 15)	

**Part X** Other Liabilities. See Form 990, Part X, line 25.

N/A

(a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, column (B) line 25)	

2 FIN 48 (ASC 740) Footnote In Part XIV, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740)

**Part XII Reconciliation of Change in Net Assets from Form 990 to Audited Financial Statements**

1	Total revenue (Form 990, Part VIII, column (A), line 12)		1,346,342.
2	Total expenses (Form 990, Part IX, column (A), line 25)		1,093,127.
3	Excess or (deficit) for the year. Subtract line 2 from line 1		253,215.
4	Net unrealized gains (losses) on investments		
5	Donated services and use of facilities		
6	Investment expenses		
7	Prior period adjustments		
8	Other (Describe in Part XIV.)		
9	Total adjustments (net) Add lines 4 through 8		
10	Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9		253,215.

**Part XIII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return**

1	Total revenue, gains, and other support per audited financial statements		1	1,346,342.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
	a Net unrealized gains on investments	2a		
	b Donated services and use of facilities	2b		
	c Recoveries of prior year grants	2c		
	d Other (Describe in Part XIV.)	2d		
	e Add lines 2a through 2d		2e	
3	Subtract line 2e from line 1		3	1,346,342.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
	a Investment expenses not included on Form 990, Part VIII, line 7b	4a		
	b Other (Describe in Part XIV.)	4b		
	c Add lines 4a and 4b		4c	
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	1,346,342.

**Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return**

1	Total expenses and losses per audited financial statements		1	1,093,127.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
	a Donated services and use of facilities	2a		
	b Prior year adjustments	2b		
	c Other losses	2c		
	d Other (Describe in Part XIV.)	2d		
	e Add lines 2a through 2d		2e	
3	Subtract line 2e from line 1		3	1,093,127.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
	a Investment expenses not included on Form 990, Part VIII, line 7b	4a		
	b Other (Describe in Part XIV.)	4b		
	c Add lines 4a and 4b		4c	
5	Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		5	1,093,127.

**Part XIV Supplemental Information**

Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, line 8; Part XII, lines 2d and 4b; and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

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**SCHEDULE O**  
**(Form 990 or 990-EZ)**

**Supplemental Information to Form 990 or 990-EZ**

OMB No 1545-0047

**2011**

Department of the Treasury  
Internal Revenue Service

Complete to provide information for responses to specific questions on  
Form 990 or 990-EZ or to provide any additional information.  
▶ Attach to Form 990 or 990-EZ.

**Open to Public  
Inspection**

Name of the organization

Employer identification number

**ADULT CONGENITAL HEART ASSOCIATION**

**04-3447959**

Pt VI, Line 3 Maison Zwes is contracted for internal accounting services.

Pt VI, Line 11a The Executive Committee reviews, in detail, the Form 990 with the  
internal accountant. Afterward, a copy of the 990 is distributed  
to the Board for final approval at a Board Meeting.

Pt VI, Line 15 Executive and key employee pay is based on the following criteria:

- 1) Performance of the individual
- 2) Market Analysis (pay comparables for position & location)
- 3) Cost of living

15a - Pay recommendation for the Executive Director is  
proposed by the Chair and then is reviewed and  
approved (or modified) by the Executive Committee  
and finally the Board.

15b - Pay recommendations for other key staff are proposed by  
the Executive Director and the Chair. It is then  
reviewed (or modified) by the Executive Committee.

Pt VI, Line 19 Copies of the required governing documents, policies and financial  
statements are distributed to the Board of Directors, and  
made available to others upon request.

Pt VI, Line 12c Every Board member receives a copy of the conflict of  
interest policy upon joining the board. Board members  
are asked to sign off on the policy upon joining the board.

Disclosures of interest conflicts, if any, are reviewed

Name of the organization

Employer identification number

ADULT CONGENITAL HEART ASSOCIATION

04-3447959

and continue to be monitored throughout the year to enable the organization to be able to address conflicts that arise in a timely manner.

Pt III, Line 3 ACHA has added new activities under several of its program as follows:

Education & Outreach Programs :

. ACHA Poster Program, ACHA Website, ACHA Blog and Congenital Heart Walk

Research Program:

. Clinicians' Perspectives on Patient Satisfaction Study

Additional detail on these activities is found on the accompanying attachment to Schedule O.

Pt VI-C, Line 18 The Form 990 is available on the Organization's website.

The Form 990 and 1023 are made available upon request.

Part VII Board / Officer names and titles:

. Peggy Powers - was also vice chair from Jan-July.

. Barry Meil - was also board chair from Jan-July.

Part VII The following were on the board for certain period during 2011, but are no longer on the board :

. Brian Altman, Bill Davidson, Kevin Gordon, David Watkins

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Schedule O (Form 990), Supplemental Information to Form 990

**Form 990, Page 2, Part III, Line 1 (continued)**

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Briefly describe the organization's mission:

heart defects. Through education, outreach, advocacy and promotion of research, ACHA serves and supports the more than one million adults with congenital heart defects, their families and medical community.

## **ACHA Program 2011**

### **Education & Outreach Activities**

Continuing Activities included:

*Heart to Heart Ambassadors:* ACHA continued to expand the Heart to Heart Ambassador Program, an initiative that provides ACHA patient and family members with personalized information and support. In 2011, 28 new Ambassadors were trained on two separate occasions—once prior to the ACHA Sixth National Conference in April, and the second time in Philadelphia in November. The original nine Ambassadors participated in the pre-conference training. Additional progress in 2011 included integrating the Heart to Heart Ambassador Program into the ACHA website, which now provides a detailed description of the program as well as an online application for becoming an Ambassador and for submitting a request for support. We've also added the "Meet Our Ambassadors" webpage, which includes each Ambassador's story and photo. ACHA Ambassadors now reach out to all new patient and family members who indicate they would like to be contacted on their membership form.

*ACHA Webinar Program:* The ACHA webinar series continues to educate CHD patients and families by presenting webinars on various interesting and timely topics. More than 800 ACHA members attended 13 different webinars in 2011. National experts spoke on a wide range of topics including "Pulmonary Hypertension in the CHD Patient," "Aging with Tetralogy of Fallot," "Women with Congenital Heart Disease: Understanding the Challenges of Pregnancy," and "ACHD, Mental Health, and Quality of Life: What Does the Data Say?" Webinars also covered topics such as ACHA advocacy and research.

*Lifelong Care Campaign:* ACHA continues to distribute two brochures targeted to educating parents and patients on the need for lifelong special care in CHD. In 2011, planning began for extending the Lifelong Care program to parents in partnership with Mended Little Hearts (MLH).

*ACHA Sixth National Conference:* ACHA's Sixth National Conference was held at the Los Angeles Airport Marriott from April 28 to May 1. This event brought together the adult congenital heart disease (ACHD) community to share the best in ACHD research and resources, celebrate our accomplishments, plan for the future and have fun. A Patient/Family Conference, a Professional Conference, and a Research Symposium ran concurrently. The faculty included national experts in the care of the adult living with CHD. Approximately 250 patient or family members and 150 ACHD health care professionals from more than 32 states, Washington, D.C., and Canada attended sessions on topics such as "Keep the Beat: Identifying and Managing Rhythm Problems," "SSI/Disability," "What Every ACHD Patient Should Know About Finding Quality ACHD Care," "Fontan Conversion: Who, What, When and How Effective?" and disease-specific breakout sessions. There was also time for fun, such as the gala reception and Beach Day. More than 95 members received financial aid to attend the conference in the form of either a Heart Heroes Scholarship or Registration Scholarship.

*ACHA Personal Health Passport:* The ACHA Personal Health Passport is designed to give members immediate access to important health information and is available online as a downloadable document and in print for all members and for ACHD clinics to distribute to their patients. It is distributed by mail

to all new patient and family members as part of a new member packet and handed out at exhibits, Congenital Heart Walks and other ACHA events.

*ACHA Discussion Forum:* A benefit of ACHA membership is the ability to participate in the online Discussion Forum. More than 7,000 members have access to this forum as a means to discuss issues with other members in the ACHA community and to provide and receive support in a moderated and safe environment.

*Travel Directory:* In collaboration with the International Society of Adult Congenital Heart Disease (ISACHD), ACHA continued to offer a print listing of CHD services to include 100+ national and international sites capable of providing emergency ACHD care to CHD patients.

*ACHD Program Directory:* Also in collaboration with ISACHD, ACHA continued to offer an online listing of more than 100 ACHD clinics in the United States and Canada; the directory continues to be the only resource of its kind available in the United States. The directory is the most frequently visited online ACHA resource. The programs in our directory with updated 2010 data have been operating for an average of 9.6 years and have medical directors with an average of 15.5 years in ACHD care. In addition, the clinics span across North America, from Honolulu, HI to Kingston, ON, Canada – over 5,500 miles apart!

*ACHA Online and Printed Materials:* ACHA provides its members information on health issues related to specific congenital heart defects. Disease-specific literature on topics such as ventricular septal defect and tetralogy of Fallot, as well as the aforementioned brochures on lifelong care for both adults and children, can be downloaded from the ACHA website.

*ACHA Facebook Page:* During 2011, ACHA updated its Facebook page multiple times per week, offering a spot for quick updates and interactivity for people who “like” ACHA. By posting ACHA Blog posts and other ACHA website content, the Facebook page also increases visibility as well as number of hits to the ACHA homepage. ACHA Facebook membership increased steadily through the year; the number of monthly active users increased was 660 in January and 1,900 by year’s end. All told, ACHA Facebook posts were viewed nearly 517,000 times in 2011, an increase of 972% from 2010. Visit the ACHA Facebook page at [www.facebook.com/AdultCongenitalHeartAssociation](http://www.facebook.com/AdultCongenitalHeartAssociation).

*ACHA E-mail Communications:* Our e-newsletter, *ACHA Update*, is regularly sent once a month to all ACHA members who have provided an e-mail address. It includes a leadership update letter from the ACHA President/CEO, plus pertinent news regarding advocacy, membership, research, development and more. In addition, ACHA members receive other announcements via e-mail, such as webinar reminders and important news updates. A portion of members who have requested it also receive targeted advocacy e-mail updates.

#### New Activities included:

*ACHA Program Poster:* The intent of the poster is to enhance our presence in the CHD community and promote ACHA through ACHD providers’ programs and clinics. The poster was created for medical professionals to display in waiting rooms and/or exam rooms so that patients could learn more about the programs that ACHA has to offer. Posters are available for free on the ACHA website.

**ACHA Website:** With continued support from the Medtronic Foundation, ACHA in 2011 worked with Reingold Inc. to develop the brand-new [www.achaheart.org](http://www.achaheart.org), which launched on March 14. The ACHA website serves as the main online portal for information, and from the launch until the end of the year; there were nearly 58,000 visits to the website. This included more than 24,000 visitors, accounting for approximately 195,000 pageviews. In 2011 new online features were launched, such as "Meet Our Ambassadors" (profiles and photos of H2H Ambassadors) and "CHD Over 60" (stories and photos of some of ACHA's older members).

**ACHA Blog:** With the launch of the new website, ACHA gained the capability to share more member stories through a blog. The ACHA Blog launched May 24, and from that date through the end of 2011, we posted 86 posts from more than 15 bloggers, which were viewed approximately 20,000 times. ACHA bloggers post on a variety of topics relevant to the CHD community, and included topics such as "Top 10 Reasons to Date a Congenital Heart Defect Survivor," "A Shout-Out to All the Moms, Especially Mine," and "The Hardest Part of Living with a CHD." The blog posts have also excelled as conversation starters on each blog's webpage, as well as on each individual posting on the ACHA Facebook page.

**Congenital Heart Walk Program:** These regional events are a joint effort between the Adult Congenital Heart Association and The Children's Heart Foundation to unite the congenital heart disease community to fight to make a difference. The walk is a way for all of those affected by CHD to help raise vital funding and awareness. In 2011, the Congenital Heart Walk's second year, more than 5,000 walkers in 19 locations across the United States raised more than \$625,000 to support and honor the millions of children, adults and families affected by CHD. The 2011 locations included Washington, D.C. Metro, Central Texas, Delaware Valley, Greater Madison, Long Island, Metro Detroit, Northern Ohio, Ohio Valley, San Francisco Bay Area, Tampa Bay, Twin Cities, Central Ohio, Central Michigan, Central Virginia, Phoenix Metro, Rio Grande Valley, Rocky Mountain, and Greater St. Louis. We also offered a virtual walk for supporters to participate outside of our walk locations. To join our efforts, visit [www.congenitalheartwalk.org](http://www.congenitalheartwalk.org).

## Research Activities

Continuing Activities included:

**Congenital Heart Public Health Consortium:** ACHA is privileged to work collaboratively with leading professional organizations and federal agencies to address CHD in the context of public health to improve awareness, education, and advocacy for the CHD community and the general public.

**REACH Project:** Awarded by the National Institutes of Health in 2010, the REACH: Research Empowerment for Adult Congenital Hearts study\* allows ACHA to collaborate with the Alliance for Adult Research in Congenital Cardiology (AARCC) to create a patient-driven, national ACHD research network. ACHA will be reaching out to the CHD patient community to inquire about their disease knowledge, access to electronic medical information and interest in research and research project participation.

**CONGENERATE Health IT Project:** ACHA continued to collaborate with AARCC and the CONGENERATE Health IT team (Montreal, Quebec, Canada) on the creation of an ACHD-specific tool for data-sharing, ACHD program management, quality improvement, and the creation of an electronic health record

(EHR) customized for CHD patients and their health care providers. ACHA's goal for CONGENERATE is to make it easier for patients to transfer data from center to center, for researchers to investigate how to improve care by sharing health information, and for ACHD specialists to provide high-quality care. More than 2,000 de-identified patient records have been pooled in one database and an abstract on this preliminary data will be presented at a medical professional conference in early 2012.

*HEART-ACHD Study:* Funded by the National Institutes of Health, ACHA continued to execute the national Health Education and Access Research Trial in Adult Congenital Heart Disease (HEART-ACHD) study\*\* at 12 participating ACHD programs, in partnership with AARCC. The study surveyed 924 new patients at ACHD centers on gaps in cardiac care, knowledge of their condition and interest in participating in research. De-identified data was pooled across the 11 participating centers and data collection was completed in January 2011. Results from the initial survey indicate that ACHD patients often have lapses in cardiology care. A first lapse most commonly occurs around 19 years old, concurrent with the time of transition from pediatric to adult providers. Lapses were more common among those with mild and moderate complexity diagnoses and at certain clinic locations. The follow-up survey results indicated that ACHD subjects were able to improve gaps in knowledge about their heart disease with a simple educational intervention. Subjects also showed a greater understanding of the process of medical research and expressed interest in future research participation. These results were presented at a medical conference in November 2011 and additional results will be presented at a medical conference in early 2012. Also as part of the project, community meetings were held in Portland, OR; Columbus and Cincinnati, OH; Milwaukee, WI; and Boston, MA. More than 150 CHD patients, family members and providers attended and received information about transition, contraception/pregnancy, surgery, education, ACHD research and the future of ACHD programs.

*Parental Knowledge Study:* This multicenter project enrolled 419 parents into this ACHA-designed and coordinated study to identify parental knowledge of their child's lifelong care needs, in partnership with the Adult Congenital Cardiac Care Associate Research Network. This study aimed to learn how to better educate parents about the need for children with congenital heart defects to maintain lifelong cardiac care (LLCC). Results showed that a substantial number of parents of children with moderate and complex CHD did not know that LLCC would be required and should be provided by an ACHD specialist. The results of this study were published in *Pediatrics*, the official journal of the American Academy of Pediatrics in November 2011.

\* The project described was supported by Award Number 1RC4HL104831 from the National Heart, Lung, and Blood Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Heart, Lung, and Blood Institute or the National Institutes of Health.

\*\*The project described was supported by Award Number R03HL096135 from the National Heart, Lung, and Blood Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Heart, Lung, and Blood Institute or the National Institutes of Health.

#### New Activities included:

*Clinicians' Perspectives on Patient Satisfaction Study:* The aim of this study was to analyze ACHD professionals' awareness of patient satisfaction and attitudes toward patient expectation. Collaborating with researchers from McGill University and Harvard University, we intended to determine if ACHD professionals receive and utilize training or a structured interventional program to manage patient expectations and improve satisfaction. 267 physicians, nurses, and physician assistants provided insight in to clinicians' awareness, attitudes and performance relative to patient satisfaction and the results will

be presented at a health care informatics conference in 2012. A manuscript detailing our findings is also in process.

## Advocacy Activities

### Continuing Activities included:

*Congenital Heart Futures Act:* ACHA continues to work to ensure that the provisions outlined in the Congenital Heart Futures Act are adequately funded and appropriately implemented. It was passed into law in 2010 and authorized investment in more research and public health surveillance to improve the lifelong well-being of congenital heart patients. In December 2011, the 2012 budget appropriated \$2 million to the Centers for Disease Control and Prevention (CDC) for congenital heart disease surveillance.

*National Congenital Heart Lobby Day:* In March 2011, ACHA once again, joined with partner organizations The Children's Heart Foundation and Mended *Little* Hearts in hosting National Congenital Heart Lobby Day in Washington, D.C. This year's event saw 33 advocates from key districts visit 42 legislative offices. The message continued to be urgent request for funding of the provisions outlined in the Congenital Heart Futures Act, including increased National Institutes of Health funding and \$7.25 million to the CDC for CHD surveillance.

*Social Security Disability and Compassionate Allowance Program:* In 2010, ACHA provided consultation to the Institute of Medicine regarding disability markers for adult patients with CHD. In 2011, access to disability was made even easier for patients with CHD through the Compassionate Allowance Program. In an unprecedented update to the list of diagnoses that would qualify for a fast track to disability, seven new diseases were added in 2011, all of which were congenital heart-related.

*Capitol Hill Briefing on Congenital Heart Defects:* In September 2011, ACHA participated in "Congenital Heart Defects: A Lifelong Disease," a congressional briefing held in Washington, D.C. ACHA President/CEO Amy Verstappen joined leading experts from the CDC, the American Academy of Pediatrics and the March of Dimes to educate Congress about the public health impact of congenital heart defects across the lifespan. This was an incredible opportunity to educate Congress about the important role of federal and state programs in congenital heart defect research, surveillance, screening and prevention. The briefing was co-hosted by Senators Durbin and Thad Cochran (R-MS), long-time champions for CHD.

*Lifelong Surveillance of Congenital Heart Disease Initiative:* ACHA has been working closely with strategic partners to help define the surveillance needs and strategies for the adult congenital heart population. ACHA has provided ongoing education to our members of congress as well as the National Center for Birth Defects and Disabilities within the CDC. These efforts directly coincide with a significant shift in priorities from the CDC that can be seen by information available on their website, specific reports to Congress about adult CHD surveillance, and serious discussion about adult CHD surveillance strategies.