

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2021

Open to Public Inspection

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations) Do not enter social security numbers on this form as it may be made public.

Go to www.irs.gov/Form990 for instructions and the latest information.

Form 990 Department of the Treasury Internal Revenue Service

For the 2021 calendar year, or tax year beginning 01-01-2021, and ending 12-31-2021

- Check if applicable: Address change, Name change, Initial return, Final 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 address) Room/suite: 280 NORTH PROVIDENCE ROAD 6
City or town, state or province, country, and ZIP or foreign postal code: MEDIA, PA 19063

D Employer identification number: 04-3447959
E Telephone number: (215) 849-1260
G Gross receipts \$ 2,384,907

F Name and address of principal officer: MARK ROEDER, 280 NORTH PROVIDENCE ROAD 6, MEDIA, PA 19063

H(a) Is this a group return for subordinates? No
H(b) Are all subordinates included? No
H(c) Group exemption number

I Tax-exempt status: 501(c)(3)

J Website: WWW.ACHAHEART.ORG

K Form of organization: Corporation

L Year of formation: 1998
M State of legal domicile: PA

Part I Summary

Table with 4 main sections: 1. Briefly describe the organization's mission... TO IMPROVE AND EXTEND THE LIVES OF MILLIONS BORN WITH CONGENITAL HEART DEFECTS. 2. Check this box if the organization discontinued its operations... 3-7a. Activities & Governance. 8-12. Revenue. 13-19. Expenses. 20-22. Net Assets or Fund Balances.

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete.

Sign Here: Signature of officer: MARK ROEDER, PRESIDENT AND CEO. Date: 2022-08-15

Paid Preparer Use Only: Print/Type preparer's name, Preparer's signature, Date, Firm's name: CLIFTONLARSONALLEN LLP, Firm's EIN: 41-0746749, Firm's address: 610 W GERMANTOWN PIKE SUITE 400, PLYMOUTH MEETING, PA 19462

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III

1 Briefly describe the organization's mission:

ADULT CONGENITAL HEART ASSOCIATION (ACHA)'S MISSION IS TO IMPROVE AND EXTEND THE LIVES OF THE MILLIONS BORN WITH HEART DEFECTS THROUGH EDUCATION, ADVOCACY, AND THE PROMOTION OF RESEARCH. ACHA SERVES AND SUPPORTS NEARLY TWO MILLION ADULTS WITH CONGENITAL HEART DEFECTS, THEIR FAMILIES AND MEDICAL COMMUNITY.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? Yes No

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

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? Yes No

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

4 Describe the 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 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 \$ 675,612 including grants of \$ 125,000) (Revenue \$ 0)
ADVOCACY, OUTREACH AND RESEARCH ACTIVITIES:-CONGRESSIONAL CONGENITAL HEART CAUCUS (39 MEMBERS TO DATE); ACHA BEGAN WORKING WITH A NEW ADVOCACY FIRM AND HOSTED AN ACHD (ADULT CONGENITAL HEART DISEASE) BRIEFING IN NOVEMBER 2021 FOR ALL MEMBERS OF CONGRESS. ACHA INVITED ACHA MEDICAL ADVISORY BOARD (MAB) MEMBERS AND MEMBERS OF THE CDC TO SPEAK. -REGIONAL DEVELOPMENT LEADERS (COVERED ONE REGION IN 2021)- RESEARCH PROGRAM (IN 2021 THE ACHA FUNDED FOUR YOUNG INVESTIGATOR RESEARCH GRANTS) CONTINUED ON SCHEDULE O.CONGRESSIONAL CONGENITAL HEART CAUCUS: THE FORMATION OF THE CONGRESSIONAL CONGENITAL HEART CAUCUS IN 2012, INITIATED BY ACHA ADVOCACY EFFORTS, IS AN INFORMAL GROUP OF MEMBERS OF CONGRESS DEDICATED TO ISSUES RELATED TO CONGENITAL HEART DEFECTS. WE ARE CONTINUALLY WORKING TO INCREASE THE NUMBER OF MEMBERS WHO SERVE ON THIS CAUCUS. AT THE END OF 2021 THERE WERE 39 MEMBERS WHO WERE A PART OF THE CONGENITAL HEART CAUCUS.

4b (Code:) (Expenses \$ 432,946 including grants of \$ 0) (Revenue \$ 157,381)
EDUCATION AND AWARENESS ACTIVITIES:-ACCREDITATION PROGRAM: FIVE NEW APPLICATIONS ACCEPTED IN 2021 WITH A TOTAL OF 44 ACCREDITED SITES AS OF YEAR END-EDUCATIONAL MATERIALS: PRINTED AND ON COMPREHENSIVE WEBSITE: ACHAHEART.ORG ALONG WITH REGIONAL CONFERENCES-PROFESSIONAL PROGRAMS: ACHA OFFERED ONE TWO-YEAR FELLOWSHIP TO VANDERBILT UNIVERSITY IN 2021. AFTER THIS ACHA WILL NO LONGER OFFER FELLOWSHIP FUNDING. -PEER SUPPORT PROGRAM: ACHA MANAGES VOLUNTEERS TO PROVIDE ONE ON ONE SUPPORT TO ACHD PATIENTS SEEKING SUCH HELP.CONTINUED ON SCHEDULE O.ACCREDITATION PROGRAM: IN 2014 ACHA AND MEMBERS OF THE MEDICAL ADVISORY BOARD (MAB) DEVELOPED A PROCESS FOR ACCREDITATION WITH 99 DIFFERENT PIECES OF CRITERIA BROKEN INTO NINETEEN DIFFERENT SECTIONS. THE ACCREDITATION PROGRAM WILL RAISE THE BAR FOR ACHD CARE IN THE UNITED STATES, ENCOURAGING ACHD PROGRAMS TO STRIVE TO MEET THE CRITERIA, WHICH WILL PROVIDE MORE AND MUCH NEEDED RESOURCES TO THE PROGRAMS AND WILL ULTIMATELY BENEFITS THE PATIENT. THROUGH THE ACCREDITATION PROGRAM WE ARE ALSO LOOKING FOR ADDITIONAL DATA COLLECTION TO SHOW THE BENEFIT OF ACCREDITATION CRITERIA MET IN A PROGRAM SETTING COMPARED TO AN ACHD PROGRAM THAT DOESN'T MEET THE NECESSARY CRITERIA. AS OF THE END OF 2021, WE HAD 44 SITES EARNING THE ACHA ACHD ACCREDITATION STATUS AND A TOTAL OF 68 SITES WHO HAVE GONE THROUGH THE PROCESS (ACCREDITATION FEE, BUSINESS ASSOCIATE AGREEMENT, SITE VISIT SCHEDULED OR COMPLETED).EDUCATIONAL MATERIALS AND WEBINARS: THROUGH ITS WEBSITE, DISCUSSION FORUMS, WEBINARS AND SOCIAL MEDIA CHANNELS, ACHA PROVIDES 24-HOUR ACCESS TO RELEVANT, UP-TO-DATE INFORMATION AND RESOURCES. FROM THE WEBINARS PATIENTS LEARN MORE ABOUT SPECIFIC CHD CONDITIONS AND DEFECTS, AND THE ISSUES THAT AFFECT THEIR LIVES. LEADING EXPERTS AND ADVOCATES COVER A RANGE OF INTERESTING, DIVERSE AND TIMELY TOPICS IN PATIENT-FRIENDLY LANGUAGE.HEART TO HEART REGIONAL CONFERENCES: ACHA NATIONAL AND REGIONAL CONFERENCES: A NATIONAL CONFERENCE WAS PLANNED FOR 2019, WHICH WAS POSTPONED TO 2020, 2021 AND THEN TO 2022. HOWEVER, DUE TO COVID, THE IN-PERSON EVENT DID NOT OCCUR. THE VIRTUAL NATIONAL CONFERENCE OCCURRED IN 2022. EXPENSES WERE INCURRED IN ALL YEARS FOR WHICH THE CONFERENCE WAS PLANNED, INCLUDING 2021. REGIONAL CONFERENCES WERE PLANNED FOR 2021 BUT HAD TO BE POSTPONED DUE TO THE COVID-19 PANDEMIC. EACH REGIONAL CONFERENCE BEGINS WITH A DYNAMIC PARTNERSHIP WITH LOCAL PATIENTS, PROFESSIONALS, AND INSTITUTIONS. EACH EVENT IS TAILORED TO REGIONAL NEEDS AND CAN INCLUDE: AN EDUCATIONAL PRESENTATION (TOPICS INCLUDE ACHA 101, ACHD OVERVIEW, DEFECT SPECIFIC INFORMATION, ETC.), GROUP ROUNDTABLES, AND EDUCATION MATERIALS AND RESOURCES. ACHD CARE GUIDELINES ARE REVIEWED AT EVERY SESSION TO ENCOURAGE LIFELONG CARE. FORUM TO DISCUSS ISSUES WITH OTHER MEMBERS IN THE ACHA COMMUNITY AND TO PROVIDE AND RECEIVE SUPPORT IN A MODERATED AND SAFE ENVIRONMENT. THERE ARE MORE THAN 9,120 MEMBERS AND 92,000 POSTS. ACHD PROGRAM DIRECTORY: IN COLLABORATION WITH THE INTERNATIONAL SOCIETY OF ADULT CONGENITAL HEART DISEASE, ACHA EXPANDED ITS ONLINE LISTING TO MORE THAN 122 ACHD CLINICS IN THE UNITED STATES AND CANADA; THE DIRECTORY CONTINUED TO BE THE ONLY RESOURCE OF ITS KIND AVAILABLE IN THE UNITED STATES.

4c (Code:) (Expenses \$ including grants of \$) (Revenue \$)

4d Other program services (Describe in Schedule O.) (Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 1,108,558

Part IV Checklist of Required Schedules

Table with 3 columns: Question number, Question text, Yes, No. Rows include questions 1 through 21 regarding organizational requirements and reporting.

Part IV Checklist of Required Schedules (continued)

		Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>		No
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>	Yes	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		No
24b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. 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>		No
25b	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>		No
26	Did the organization report any amount on Part X, line 5 or 22 for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons?		No
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		No
28	Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
28a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>		No
28b	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		No
28c	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions?		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		No
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>		No
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?		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		No
35b	If "Yes" to line 35a, 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>		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		No
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>		No
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O.	Yes	

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V

		Yes	No
1a	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable		
1b	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable		
1c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	2a	15			
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.	2b	Yes			
3a Did the organization have unrelated business gross income of \$1,000 or more during the year? . . .	3a		No		
b If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation in Schedule O</i> . . .	3b				
4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? Enter the name of the foreign country: _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).	4a		No		
5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . .	5a		No		
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		No		
c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?	5c				
6a 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 as charitable contributions? . . .	6a		No		
b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b				
7 Organizations that may receive deductible contributions under section 170(c).					
a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	Yes			
b If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	Yes			
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		No		
d If "Yes," indicate the number of Forms 8282 filed during the year	7d				
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		No		
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		No		
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g				
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h				
8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8				
9 Sponsoring organizations maintaining donor advised funds.					
a Did the sponsoring organization make any taxable distributions under section 4966?	9a				
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . .	9b				
10 Section 501(c)(7) organizations. Enter:					
a Initiation fees and capital contributions included on Part VIII, line 12	10a				
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b				
11 Section 501(c)(12) organizations. Enter:					
a Gross income from members or shareholders	11a				
b Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b				
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?					
b If "Yes," enter the amount of tax-exempt interest received or accrued during the year.	12b				
13 Section 501(c)(29) qualified nonprofit health insurance issuers.					
a Is the organization licensed to issue qualified health plans in more than one state?	13a				
Note. See the instructions for additional information the organization must report on Schedule O.					
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	13b				
c Enter the amount of reserves on hand	13c				
14a Did the organization receive any payments for indoor tanning services during the tax year?	14a		No		
b If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation in Schedule O</i> . .	14b				
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year?	15		No		
16 If the organization is a trust, did it file Form 720, Schedule E, to report the section 4968 excise tax on net investment income?	16		No		
Note. If "Yes," complete Form 4720, Schedule O.					
17 Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? . .	17				
If "Yes," complete Form 6069.					

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



Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members... 2 Did any officer, director, trustee... 3 Did the organization delegate control... 4 Did the organization make any significant changes... 5 Did the organization become aware... 6 Did the organization have members... 7a Did the organization have members... 7b Are any governance decisions... 8 Did the organization contemporaneously document... 8a The governing body... 8b Each committee... 9 Is there any officer, director, trustee...

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... 10b If "Yes," did the organization have written policies... 11a Has the organization provided a complete copy... 11b Describe on Schedule O the process... 12a Did the organization have a written conflict of interest policy... 12b Were officers, directors, or trustees... 12c Did the organization regularly and consistently monitor... 13 Did the organization have a written whistleblower policy... 14 Did the organization have a written document retention... 15 Did the process for determining compensation... 15a The organization's CEO... 15b Other officers or key employees... 16a Did the organization invest in, contribute assets to... 16b If "Yes," did the organization follow a written policy...

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed: CA, CO, FL, GA, IL, KY, MD, MA, MI, MN, NE, NH, NJ, NM, NY, OH, OK, OR, PA, TN, UT, VA, WI, MO, SC, WA, DC
18 Section 6104 requires an organization to make its Form 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records: THE ORGANIZATION 280 NORTH PROVIDENCE ROAD 6 MEDIA, PA 19063 (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 or note to any line 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 the 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, Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
 - List all of the organization's **former** officers, key employees, or 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.
- See the instructions for the order in which to list the persons above.

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 (list any hours for related organizations below dotted line)	(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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) JEFF ISHIDA CHAIR	2.00	X		X				0	0	0
(2) JAMES RUPPEL MD MS VICE CHAIR	2.00	X		X				0	0	0
(3) TOM WIX TREASURER	2.00	X		X				0	0	0
(4) SUSAN TIMMINS SECRETARY	2.00	X		X				0	0	0
(5) HEATHER ABBOTT BOARD MEMBER	2.00	X						0	0	0
(6) JAMIL ABOULHOSN MD BOARD MEMBER	2.00	X						0	0	0
(7) RONNIE ALTMAN BOARD MEMBER	2.00	X						0	0	0
(8) STEPHEN BACK BOARD MEMBER	2.00	X						0	0	0
(9) MINDY BEYER BOARD MEMBER	2.00	X						0	0	0
(10) WEB BROWNE BOARD MEMBER	2.00	X						0	0	0
(11) CINDY HUIE BOARD MEMBER	2.00	X						0	0	0
(12) NEEMA KHATRI BOARD MEMBER	2.00	X						0	0	0
(13) RICHARD KRASUSKI MD BOARD MEMBER	2.00	X						0	0	0
(14) MICHAEL LANDZBERG BOARD MEMBER	2.00	X						0	0	0
(15) ALIZA MARLIN BOARD MEMBER	2.00	X						0	0	0
(16) JOANNE NICHOLS BOARD MEMBER	2.00	X						0	0	0
(17) MICHAEL PERNICK BOARD MEMBER	2.00	X						0	0	0

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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				
(18) ARWA SAIDI MD BOARD MEMBER	2.00	X						0	0	0	
(19) MARK ROEDER PRESIDENT AND CEO	50.00			X				166,754	0	8,520	
(20) BETH COIMBRA DIRECTOR OF FINANCE	40.00			X				95,283	0	15,794	
1b Sub-Total											
c Total from continuation sheets to Part VII, Section A											
d Total (add lines 1b and 1c)								262,037	0		24,314

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 **▶ 1**

	Yes	No
3 Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
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? <i>If "Yes," complete Schedule J for such individual</i>	Yes	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

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 of compensation from the organization **▶ 0**

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII

	(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514
Contributions, Gifts, Grants, and Other Amt Similar Amounts				
1a Federated campaigns		1a		
b Membership dues		1b	26,685	
c Fundraising events		1c		
d Related organizations		1d		
e Government grants (contributions)		1e	495,815	
f All other contributions, gifts, grants, and similar amounts not included above		1f	1,331,921	
g Noncash contributions included in lines 1a - 1f:\$		1g		
h Total. Add lines 1a-1f				1,854,421

Program Service Revenue	2a PROGRAM AND EVENTS	Business Code	(A)	(B)	(C)	(D)
		900099	157,381	157,381		
b						
c						
d						
e						
f All other program service revenue.						
g Total. Add lines 2a-2f.		157,381				

Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		12,760			12,760	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6a Gross rents	(i) Real					
		(ii) Personal					
		6b Less: rental expenses					
		6c Rental income or (loss)					
	d Net rental income or (loss)						
	7a Gross amount from sales of assets other than inventory	(i) Securities	360,345				
		(ii) Other					
		7b Less: cost or other basis and sales expenses	259,431				
		7c Gain or (loss)	100,914				
	d Net gain or (loss)		100,914			100,914	
	8a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18						
		8b Less: direct expenses					
	c Net income or (loss) from fundraising events						
	9a Gross income from gaming activities. See Part IV, line 19						
		9b Less: direct expenses					
	c Net income or (loss) from gaming activities						
	10a Gross sales of inventory, less returns and allowances						
10b Less: cost of goods sold							
c Net income or (loss) from sales of inventory							
Miscellaneous Revenue	Business Code						
11a							
b							
c							
d All other revenue							
e Total. Add lines 11a-11d							
12 Total revenue. See instructions			2,125,476	157,381	0	113,674	

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).

Check if Schedule O contains a response or note to any line in this Part IX

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	125,000	125,000		
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	286,351	63,690	166,746	55,915
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	694,137	529,801	33,250	131,086
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	13,365	9,879	398	3,088
9 Other employee benefits	78,340	57,495	4,640	16,205
10 Payroll taxes	82,885	51,088	15,850	15,947
11 Fees for services (non-employees):				
a Management				
b Legal	13,070	10,300	1,381	1,389
c Accounting	15,405	9,495	2,946	2,964
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	140,671	124,231	6,692	9,748
12 Advertising and promotion				
13 Office expenses	79,371	47,275	2,587	29,509
14 Information technology	78,219	53,864	4,948	19,407
15 Royalties				
16 Occupancy	18,721	11,539	3,580	3,602
17 Travel	462	285	88	89
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	8,754	6,290	1,228	1,236
23 Insurance	5,976	3,683	1,143	1,150
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 LICENSES/SUBSCRIPTIONS	7,533	4,643	1,441	1,449
b				
c				
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	1,648,260	1,108,558	246,918	292,784
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

Check if Schedule O contains a response or note to any line in this Part IX

		(A) Beginning of year		(B) End of year
Assets	1 Cash-non-interest-bearing	728,203	1	998,416
	2 Savings and temporary cash investments	58,468	2	110,463
	3 Pledges and grants receivable, net	437,390	3	215,848
	4 Accounts receivable, net		4	
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	51,810	9	69,467
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 118,163		
	b Less: accumulated depreciation	10b 103,410	13,972	10c 14,753
	11 Investments—publicly traded securities	327,670	11	364,860
	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	1,715	15	1,715
16 Total assets: Add lines 1 through 15 (must equal line 33)	1,619,228	16	1,775,522	
Liabilities	17 Accounts payable and accrued expenses	55,857	17	59,831
	18 Grants payable		18	
	19 Deferred revenue	194,306	19	202,171
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties	262,300	24	0
	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 Total liabilities. Add lines 17 through 25	512,463	26	262,002
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	443,935	27	968,995
	28 Net assets with donor restrictions	662,830	28	544,525
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	1,106,765	32	1,513,520
33 Total liabilities and net assets/fund balances	1,619,228	33	1,775,522	

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response or note to any line in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,125,476
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,648,260
3	Revenue less expenses. Subtract line 2 from line 1	3	477,216
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	1,106,765
5	Net unrealized gains (losses) on investments	5	-70,461
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	10	1,513,520

Part XII Financial Statements and Reporting

Check if Schedule O contains a response or note to any line in this Part XII

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
2b	Were the organization's financial statements audited by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
2c	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.	Yes	
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?		No
3b	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.		

Additional Data

Return to Form

Software ID:

Software Version:

Form 990, Special Condition Description:

Special Condition Description

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.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Name of the organization
ADULT CONGENITAL HEART ASSOCIATION

Employer identification number
04-3447959

Part I 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 12, 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 (Form 990).)
- 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 agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture. See instructions. Enter the name, city, and state of the college or university:
- 10 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.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to 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 on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - a **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
 - b **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
 - f Enter the number of supported organizations _____
 - g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

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 failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 Value of services or facilities furnished; 4 Total; 5 Portion of total contributions exceeding 2%; 6 Public support.

Section B. Total Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 9 Net income from unrelated business activities; 10 Other income; 11 Total support; 12 Gross receipts from related activities; 13 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Line number, Percentage. Rows include: 14 Public support percentage for 2021 (80.520%); 15 Public support percentage for 2020 Schedule A, Part II, line 14 (78.530%); 16a 33 1/3% support test-2021; 16b 33 1/3% support test-2020; 17a 10%-facts-and-circumstances test-2021; 17b 10%-facts-and-circumstances test-2020; 18 Private foundation.

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 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 year beginning in) ►	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .						
2 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						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
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.						
c Add lines 7a and 7b. .						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
9 Amounts from line 6.						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
c Add lines 10a and 10b.						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on.						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First 5 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

15 Public support percentage for 2021 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2020 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2021 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2020 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2021. 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—2020. 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

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, of Part I, complete Sections A and B. If you checked box 12b, of Part I, complete Sections A and C. If you checked box 12c, of Part I, complete Sections A, D, and E. If you checked box 12d, of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

		Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
b	Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
c	Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		

Part IV Supporting Organizations (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization?		
b A family member of a person described on 11a above?		
c A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI</i>		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3 By reason of the relationship described in line 2 above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (**see instructions**):

- a** The organization satisfied the Activities Test. Complete **line 2** below.
- b** The organization is the parent of each of its supported organizations. Complete **line 3** below.
- c** The organization supported a governmental entity. Describe in **Part VI** how you supported a government entity (see instructions)

2 Activities Test. **Answer lines 2a and 2b below.**

	Yes	No
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
b Did the activities described on line 2a, above constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		

3 Parent of Supported Organizations. **Answer lines 3a and 3b below.**

	Yes	No
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No", provide details in Part VI.</i>		
b Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

- 1** Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in **Part VI**). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income

(A) Prior Year

(B) Current Year
(optional)

- | | | | |
|---|----------|--|--|
| 1 Net short-term capital gain | 1 | | |
| 2 Recoveries of prior-year distributions | 2 | | |
| 3 Other gross income (see instructions) | 3 | | |
| 4 Add lines 1 through 3 | 4 | | |
| 5 Depreciation and depletion | 5 | | |
| 6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6 | | |
| 7 Other expenses (see instructions) | 7 | | |
| 8 Adjusted Net Income (subtract lines 5, 6 and 7 from line 4) | 8 | | |

Section B - Minimum Asset Amount

(A) Prior Year

(B) Current Year
(optional)

- | | | | |
|--|-----------|--|--|
| 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | 1 | | |
| a Average monthly value of securities | 1a | | |
| b Average monthly cash balances | 1b | | |
| c Fair market value of other non-exempt-use assets | 1c | | |
| d Total (add lines 1a, 1b, and 1c) | 1d | | |
| e Discount claimed for blockage or other factors (explain in detail in Part VI): | | | |
| 2 Acquisition indebtedness applicable to non-exempt use assets | 2 | | |
| 3 Subtract line 2 from line 1d | 3 | | |
| 4 Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions). | 4 | | |
| 5 Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | | |
| 6 Multiply line 5 by 0.035 | 6 | | |
| 7 Recoveries of prior-year distributions | 7 | | |
| 8 Minimum Asset Amount (add line 7 to line 6) | 8 | | |

Section C - Distributable Amount

Current Year

- | | | |
|--|----------|--|
| 1 Adjusted net income for prior year (from Section A, line 8, Column A) | 1 | |
| 2 Enter 85% of line 1 | 2 | |
| 3 Minimum asset amount for prior year (from Section B, line 8, Column A) | 3 | |
| 4 Enter greater of line 2 or line 3 | 4 | |
| 5 Income tax imposed in prior year | 5 | |
| 6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | 6 | |

- 7** Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

(continued)

Section D - Distributions		Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (prior IRS approval required - provide details in Part VI)	5	
6 Other distributions (describe in Part VI). See instructions	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions	8	
9 Distributable amount for 2021 from Section C, line 6	9	
10 Line 8 amount divided by Line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2021	(iii) Distributable Amount for 2021
1 Distributable amount for 2021 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2021 (reasonable cause required-- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2021:			
a From 2016.			
b From 2017.			
c From 2018.			
d From 2019.			
e From 2020.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2021 distributable amount			
i Carryover from 2016 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2021 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2021 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2022. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2017.			
b Excess from 2018.			
c Excess from 2019.			
d Excess from 2020.			
e Excess from 2021.			

Part VI Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Return Reference	Explanation
SCHEDULE A, PART II, LINE 10, EXPLANATION OF OTHER INCOME:	OTHER REVENUE - 2017 AMOUNT: \$ 940. 2018 AMOUNT: \$ 148. 2019 AMOUNT: \$ 373. 2020 AMOUNT: \$ 535. 2021 AMOUNT: \$ 0.

Additional Data

Return to Form

Software ID:

Software Version:

Political Campaign and Lobbying Activities
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.**
▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

If the organization answered "Yes" on 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" on 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" on Form 990, Part IV, Line 5 (Proxy Tax) (see separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then

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

Name of the organization ADULT CONGENITAL HEART ASSOCIATION	Employer identification number 04-3447959
--	---

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

1	Provide a description of the organization's direct and indirect political campaign activities in Part IV. See instructions for definition of "political campaign activities."		
2	Political campaign activity expenditures. See instructions	▶	\$ _____
3	Volunteer hours for political campaign activities. See instructions		_____

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

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?		<input type="checkbox"/> Yes <input type="checkbox"/> No
4a	Was a correction made?		<input type="checkbox"/> Yes <input type="checkbox"/> No
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).

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?		<input type="checkbox"/> Yes <input type="checkbox"/> 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-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

- A** Check if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).
- B** Check if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliated group totals												
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)														
b Total lobbying expenditures to influence a legislative body (direct lobbying)														
c Total lobbying expenditures (add lines 1a and 1b)														
d Other exempt purpose expenditures														
e Total exempt purpose expenditures (add lines 1c and 1d)														
f Lobbying nontaxable amount. Enter the amount from the following table in both columns.														
<table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th style="width:50%; text-align:left;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width:50%; text-align:left;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table>	If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e.	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	Over \$17,000,000	\$1,000,000.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:													
Not over \$500,000	20% of the amount on line 1e.													
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.													
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.													
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.													
Over \$17,000,000	\$1,000,000.													
g Grassroots nontaxable amount (enter 25% of line 1f)														
h Subtract line 1g from line 1a. If zero or less, enter -0-														
i Subtract line 1f from line 1c. If zero or less, enter -0-														
j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?	<input type="checkbox"/> Yes <input type="checkbox"/> No													

4-Year Averaging Period Under Section 501(h)
(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

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 on 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?	Yes		
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	Yes		
c Media advertisements?		No	
d Mailings to members, legislators, or the public?		No	
e Publications, or published or broadcast statements?		No	
f Grants to other organizations for lobbying purposes?		No	
g Direct contact with legislators, their staffs, government officials, or a legislative body?		No	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		No	
i Other activities?		No	
j Total. Add lines 1c through 1i			0
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		No	
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).

	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."

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

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions), and Part II-B, line 1. Also, complete this part for any additional information.

Return Reference	Explanation
PART II-B, LINE 1:	CONGRESSIONAL CONGENITAL HEART CAUCUS: THE FORMATION OF THE CONGRESSIONAL CONGENITAL HEART CAUCUS IN 2012, INITIATED BY ACHA ADVOCACY EFFORTS, IS AN INFORMAL GROUP OF MEMBERS OF CONGRESS DEDICATED TO ISSUES RELATED TO CONGENITAL HEART DEFECTS. AT THE END OF 2021 THE CAUCUS CONSISTS OF 39 MEMBERS. IN-DISTRICT ADVOCACY INITIATIVE: ACHA GUIDED ITS CONSTITUENTS TO SCHEDULE MEETINGS WITH THEIR FEDERAL LEGISLATORS WHILE THEY WERE IN THEIR HOME OFFICES. ACHA WORKED WITH ABOUT 100 CONSTITUENTS FROM 25 STATES TO REACH OUT TO LEGISLATORS TO INFORM THEM ABOUT ACHA, AND DISCUSS ACCESS TO CARE AND LEGISLATIVE NEXT STEPS FOR ACHD PATIENTS.

Additional Data

Return to Form

Software ID:

Software Version:

Supplemental Financial Statements

2021

Open to Public Inspection

▶ **Complete if the organization answered "Yes," on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.**
▶ **Attach to Form 990.**

▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

Department of the Treasury
Internal Revenue Service

Name of the organization

ADULT CONGENITAL HEART ASSOCIATION

Employer identification number

04-3447959

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of 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? Yes 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? Yes No

Part II Conservation Easements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).
 Preservation of land for public use (e.g., recreation or education) Preservation of an historically important land area
 Protection of natural habitat Preservation of a certified historic structure
 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 Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register	2d

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, handling of violations, and enforcing conservation easements during the year
▶ _____

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, 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 XIII, 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" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB 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 XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under FASB 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) Revenue included on 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 FASB ASC 958 relating to these items:

a Revenue included on 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 XIII.
- 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" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a** 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 XIII 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 |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? **Yes** **No**
- b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds.

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a 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** Term endowment ▶
- The percentages on lines 2a, 2b, and 2c should equal 100%.

- 3a** 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" on 3a(ii), are the related organizations listed as required on Schedule R? | 3b | |
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. 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
1a Land				
b Buildings				
c Leasehold improvements		4,322	1,809	2,513
d Equipment		113,841	101,601	12,240
e Other				
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . ▶				14,753

Part VII Investments - Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(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)		
Total. (Column (b) must equal Form 990, Part X, col. (B) line 12.)		

Part VIII Investments - Program Related.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

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

Part IX Other Assets.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

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

Part X Other Liabilities.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

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

2. Liability for uncertain tax positions. In Part XIII, 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). Check here if the text of the footnote has been provided in Part XIII

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	2,145,615
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	-70,461	
b	Donated services and use of facilities	2b	90,600	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d			2e 20,139
3	Subtract line 2e from line 1			3 2,125,476
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 XIII.)	4b		
c	Add lines 4a and 4b			4c 0
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)			5 2,125,476

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	1,738,860
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	90,600	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d			2e 90,600
3	Subtract line 2e from line 1			3 1,648,260
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 XIII.)	4b		
c	Add lines 4a and 4b			4c 0
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)			5 1,648,260

Part XIII Supplemental Information

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, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

Return Reference	Explanation
PART X, LINE 2:	ACHA IS RECOGNIZED AS AN ORGANIZATION EXEMPT FROM FEDERAL INCOME TAX UNDER SECTION 501(C)(3) OF THE INTERNAL REVENUE CODE OF 1986. THE ORGANIZATION QUALIFIES FOR CHARITABLE CONTRIBUTION DEDUCTIONS AND IS CLASSIFIED AS AN ORGANIZATION THAT IS NOT A PRIVATE FOUNDATION. INCOME THAT IS NOT RELATED TO EXEMPT PURPOSES, LESS APPLICABLE DEDUCTIONS, WOULD BE SUBJECT TO FEDERAL AND STATE CORPORATE INCOME TAXES. ACHA HAD NO NET UNRELATED BUSINESS INCOME FOR THE YEARS ENDED DECEMBER 31, 2021 AND 2020. MANAGEMENT EVALUATED ACHA'S TAX POSITIONS AND CONCLUDED THAT ACHA HAD TAKEN NO UNCERTAIN TAX POSITIONS THAT REQUIRE ADJUSTMENT TO THE FINANCIAL STATEMENTS. CONSEQUENTLY, NO ACCRUAL FOR INTEREST AND PENALTIES WAS DEEMED NECESSARY FOR THE YEARS ENDED DECEMBER 31, 2021 AND 2020.

Additional Data

[**Return to Form**](#)

Software ID:

Software Version:

**Schedule I
(Form 990)**

**Grants and Other Assistance to Organizations,
Governments and Individuals in the United States**

OMB No. 1545-0047

2021

**Open to Public
Inspection**

Department of the
Treasury
Internal Revenue Service

Complete if the organization answered "Yes," on Form 990, Part IV, line 21 or 22.

▶ Attach to Form 990.

▶ Go to www.irs.gov/Form990 for the latest information.

Name of the organization
ADULT CONGENITAL HEART ASSOCIATION

Employer identification number
04-3447959

Part I General Information on Grants and Assistance

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- 2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA 3451 WALNUT STREET PHILADELPHIA, PA 19104	23-1352685	501(C)(3)	15,000	0			RESEARCH AWARD
(2) CHILDREN'S HOSPITAL MEDICAL CENTER 333 BURNET AVENUE CINCINNATI, OH 452293039	31-0833936	501(C)(3)	15,000	0			RESEARCH AWARD
(3) TRUSTEES OF COLUMBIA UNIVERSITY 615 WEST 131ST STREET MC 8741 NEW YORK, NY 10027	91-1859360	501(C)(2)	32,500	0			RESEARCH AWARD
(4) BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	32,500	0			RESEARCH AWARD
(5) UC REGENTS 220 MONTGOMERY ST FL 5 SAN FRANCISCO, CA 94104	94-6036493	501(C)(3)	15,000	0			RESEARCH AWARD
(6) UNIVERSITY OF IOWA 108 CALVIN HALL IOWA CITY, IA 52242	42-6004813		15,000	0			RESEARCH AWARD

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 4
- 3** Enter total number of other organizations listed in the line 1 table 2

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Return Reference	Explanation
PART I, LINE 2:	RESEARCH GRANTS: ACHA MANAGES THE APPLICATION PROCESS, WITH A TEAM OF MEDICAL PROVIDERS AND PATIENT/FAMILY MEMBERS WHO REVIEW EACH OF THE RESEARCH APPLICATIONS WITH REDACTED INFORMATION ABOUT THE MEDICAL PROVIDERS AND INSTITUTION INVOLVED IN THE RESEARCH PROJECT. EACH RESEARCH APPLICATION IS REVIEWED AND ASSIGNED A SCORE BASED ON A PREDETERMINED SET OF CRITERIA. THE RESEARCH GRANTS WITH THE HIGHEST SCORES FROM BOTH THE MEDICAL PROVIDERS AND LAY REVIEWERS (PATIENTS AND FAMILY MEMBERS) ARE AWARDED THE FUNDS ALLOTTED. INTERESTED RESEARCHERS APPLY THROUGH ACHA. RESEARCHERS AWARDED FUNDS THROUGH ACHA ARE REQUIRED TO SUBMIT QUARTERLY REPORTS TO ACHA INCLUDING A DETAILED FINANCIAL REPORT.

Additional Data

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Schedule J
(Form 990)

Compensation Information

OMB No. 1545-0047

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

- ▶ **Complete if the organization answered "Yes" on Form 990, Part IV, line 23.**
- ▶ **Attach to Form 990.**
- ▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

2021

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization
ADULT CONGENITAL HEART ASSOCIATION

Employer identification number

04-3447959

Part I Questions Regarding Compensation

1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

- | | |
|---|--|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax idemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef) |

b If any of the boxes on Line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, officers, including the CEO/Executive Director, regarding the items checked on Line 1a?

3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

- | | |
|---|---|
| <input checked="" type="checkbox"/> Compensation committee | <input type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input checked="" type="checkbox"/> Compensation survey or study |
| <input checked="" type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

4 During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a** Receive a severance payment or change-of-control payment?
 - b** Participate in, or receive payment from, a supplemental nonqualified retirement plan?
 - c** Participate in, or receive payment from, an equity-based compensation arrangement?
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

Only 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.

5 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

- a** The organization?
 - b** Any related organization?
- If "Yes," on line 5a or 5b, describe in Part III.

6 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

- a** The organization?
 - b** Any related organization?
- If "Yes," on line 6a or 6b, describe in Part III.

7 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described in lines 5 and 6? If "Yes," describe in Part III.

8 Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III.

9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

	Yes	No
1b		
2		
4a		No
4b		No
4c		No
5a		No
5b		No
6a		No
6b		No
7		No
8		No
9		

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

Return Reference	Explanation
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SCHEDULE O
(Form 990)**Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

2021**Open to Public
Inspection**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.**▶ **Go to www.irs.gov/Form990 for the latest information.**Name of the organization
ADULT CONGENITAL HEART ASSOCIATION**Employer identification number**

04-3447959

Return Reference	Explanation
FORM 990, PART V, LINES 1 AND 2:	ACHA EMPLOYEES ARE PAID THROUGH A THIRD-PARTY PROFESSIONAL EMPLOYER ORGANIZATION (PEO). THE PEO (EIN 76-0689539) IS THE EMPLOYER OF RECORD AND ASSUMES THE RESPONSIBILITY OF REPORTING AND REMITTING ALL TAXES WITHHELD FROM ACHA WAGES.
FORM 990, PART VI, SECTION A, LINE 1A	THE EXECUTIVE COMMITTEE IS COMPRISED OF THE CHAIR, VICE CHAIR, TREASURER, SECRETARY, AND THE IMMEDIATE PAST CHAIR. THEY HAVE AND MAY EXERCISE THE POWERS AND AUTHORITY OF THE BOARD, EXCEPT THAT NO COMMITTEE, INCLUDING BUT NOT LIMITED TO THE EXECUTIVE COMMITTEE, SHALL HAVE ANY POWER OR AUTHORITY AS TO THE FOLLOWING: 1) THE FILLING OF VACANCIES ON THE BOARD, 2) THE ADOPTION, AMENDMENT OR REPEAL OF THE BYLAWS, 3) THE AMENDMENT OR REPEAL OF ANY RESOLUTION OF THE BOARD, OR 4) ACTION ON MATTERS COMMITTED BY THE BYLAWS OR BY RESOLUTION OF THE BOARD TO ANOTHER COMMITTEE OF THE BOARD.
FORM 990, PART VI, SECTION A, LINE 4	DURING 2021, ADULT CONGENITAL HEART ASSOCIATION UPDATED ITS BYLAWS. THERE WERE SEVERAL SIGNIFICANT CHANGES. 1) THE REQUIREMENT FOR BOARD MEMBER QUALIFICATIONS CHANGED FROM 51% OF DIRECTORS NEEDING TO BE ADULTS DIRECTLY AFFECTED BY CONGENITAL HEART DISEASE OR THEIR FAMILY MEMBERS TO 25% NEEDING TO BE DIRECTLY AFFECTED. 2) NON-DIRECTORS ON COMMITTEES PREVIOUSLY COULD NOT VOTE, BUT THEY NOW HAVE THE POWER TO VOTE ON ANY MATTER BEFORE THE COMMITTEE, PROVIDED THAT SAID MATTER IS SUBSEQUENTLY REFERRED TO THE BOARD FOR FINAL EXERCISE OF POWER AND AUTHORITY BEFORE ENACTMENT. 3) ON APRIL 18, 2021, THE PATIENT FAMILY ADVISORY BOARD (PFAB) WAS ESTABLISHED. THIS BOARD ELECTS TWO OFFICERS TO SERVE ON THE FULL BOARD OF DIRECTORS, SIMILAR TO THE THREE SEATS THE MEDICAL ADVISORY BOARD IS ALLOWED.
FORM 990, PART VI, SECTION B, LINE 11B	THE FORM 990 IS PREPARED BY AN INDEPENDENT ACCOUNTING FIRM THEN THE AUDIT COMMITTEE REVIEWS, IN DETAIL, THE DRAFT FORM 990 WITH THE INTERNAL ACCOUNTANT. AFTERWARD, A DRAFT COPY OF THE FORM 990 IS MADE AVAILABLE TO THE BOARD BEFORE FINAL FILING.
FORM 990, PART VI, SECTION B, LINE 12C	ANNUALLY EVERY BOARD MEMBER RECEIVES A COPY OF THE CONFLICT OF INTEREST POLICY AND IS ASKED TO SIGN OFF ON THE POLICY AT THAT TIME. POTENTIAL CONFLICTS ARE REPORTED TO THE PRESIDENT OR THE BOARD. IF THERE IS A CONFLICT OR POTENTIAL CONFLICT, THE BOARD MEMBER WILL RECUSE THEMSELVES FROM DELIBERATION AND ANY VOTE OVER THE MATTER. DISCLOSURES OF POTENTIAL CONFLICTS, IF ANY, ARE REVIEWED AND CONTINUE TO BE MONITORED THROUGHOUT THE YEAR TO ENABLE THE ORGANIZATION TO BE ABLE TO ADDRESS CONFLICTS THAT ARISE IN A TIMELY MANNER.
FORM 990, PART VI, SECTION B, LINE 15	ALL OFFICER AND KEY EMPLOYEE PAY IS BASED ON THE FOLLOWING CRITERIA: 1) PERFORMANCE OF THE INDIVIDUAL, 2) MARKET ANALYSIS (PAY COMPARABLES FOR POSITION AND LOCATION), 3) COST OF LIVING. THIS REVIEW PROCESS AND THE FINAL DETERMINATIONS ARE TIMELY DOCUMENTED IN THE BOARD MINUTES WITH THE APPROVAL OF THE ANNUAL BUDGET. FORM 990, PART VI, SECTION B, LINE 15A: THE PAY RECOMMENDATION FOR THE PRESIDENT AND CEO IS PROPOSED BY THE CHAIR AND IS THEN REVIEWED AND APPROVED (OR MODIFIED) BY THE CHAIR, VICE CHAIR AND GOVERNANCE CHAIR, AND THEN FINALLY THE BOARD. FORM 990, PART VI, SECTION B, LINE 15B: PAY RECOMMENDATION FOR OTHER OFFICERS AND KEY EMPLOYEES ARE PROPOSED BY THE PRESIDENT AND CEO AND THE CHAIR. THEY ARE THEN REVIEWED AND APPROVED (OR MODIFIED) BY THE BOARD DURING THE BUDGET APPROVAL PROCESS FOR PERSONNEL EXPENSES.
FORM 990, PART VI, SECTION C, LINE 19	COPIES OF THE GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND FINANCIAL STATEMENTS ARE DISTRIBUTED TO THE BOARD OF DIRECTORS, AND ARE MADE AVAILABLE TO OTHERS UPON REQUEST.

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