

Short Form

Return of Organization Exempt From Income Tax

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

OMB No 1545-1150

2008

Open to Public Inspection

Form 990-EZ

Department of the Treasury
Internal Revenue Service

▶ Sponsoring organizations of donor advised funds and controlling organizations as defined in section 512(b)(13) must file Form 990. All other organizations with gross receipts less than \$1,000,000 and total assets less than \$2,500,000 at the end of the year may use this form.

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

A For the 2008 calendar year, or tax year beginning

and ending

B Check if applicable

- ☐ Address change
☐ Name change
☐ Initial return
☐ Termination
☐ Amended return
☐ Application pending

Please use IRS label or print or type See Specific Instructions

C Name of organization

ARPKD/CHF ALLIANCE

Number and street (or P.O. box, if mail is not delivered to street address)

38 JOHN DRIVE

City or town, state or country, and ZIP + 4

KIRKWOOD, PA 17536

D Employer identification number

23-3069557

E Telephone number

717-529-5555

F Group Exemption Number

▶

• Section 501(c)(3) organizations and 4947(a)(1) nonexempt charitable trusts must attach a completed Schedule A (Form 990 or 990-EZ).

G Accounting method: ☐ Cash ☒ Accrual
Other (specify) ▶

I Website: ▶ WWW.ARPKD.ORG

J Organization type (check only one) — ☒ 501(c) (3) ◀ (insert no.) ☐ 4947(a)(1) or ☐ 527

H Check ☒ if the organization is not required to attach Schedule B (Form 990, 990-EZ, or 990-PF)

K Check ☐ if the organization is not a section 509(a)(3) supporting organization and its gross receipts are normally not more than \$25,000. A return is not required, but if the organization chooses to file a return, be sure to file a complete return.

L Add lines 5b, 6b, and 7b, to line 9 to determine gross receipts; if \$1,000,000 or more, file Form 990 instead of Form 990-EZ ▶ \$ 44,088.

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (See the instructions for Part I.)

Revenue	1	Contributions, gifts, grants, and similar amounts received	1	43,153.
	2	Program service revenue including government fees and contracts	2	
	3	Membership dues and assessments	3	
	4	Investment income	4	
	5a	Gross amount from sale of assets other than inventory	5a	
	b	Less: cost or other basis and sales expenses	5b	
	c	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a) (attach schedule)	5c	
	6	Special events and activities (complete applicable parts of Schedule G). If any amount is from gaming, check here <input type="checkbox"/>		
	a	Gross revenue (not including \$ of contributions reported on line 1)	6a	
b	Less: direct expenses other than fundraising expenses	6b		
c	Net income or (loss) from special events and activities (Subtract line 6b from line 6a)	6c		
7a	Gross sales of inventory, less returns and allowances	7a		
b	Less: cost of goods sold	7b		
c	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)	7c		
8	Other revenue (describe ▶ INTEREST INCOME)	8	935.	
9	Total revenue Add lines 1, 2, 3, 4, 5c, 6c, 7c, and 8	9	44,088.	
Expenses	10	Grants and similar amounts paid (attach schedule)	10	25,000.
	11	Benefits paid to or for members	11	
	12	Salaries, other compensation, and employee benefits	12	29,671.
	13	Professional fees and other payments to independent contractors	13	1,833.
	14	Occupancy, rent, utilities, and maintenance	14	
	15	Printing, publications, postage, and shipping	15	6,873.
	16	Other expenses (describe ▶ SEE STATEMENT 1)	16	22,241.
	17	Total expenses. Add lines 10 through 16	17	85,618.
Net Assets	18	Excess or (deficit) for the year (Subtract line 17 from line 9)	18	<41,530.>
	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return)	19	120,895.
	20	Other changes in net assets or fund balances (attach explanation)	20	
	21	Net assets or fund balances at end of year. Combine lines 18 through 20	21	79,365.

Part II Balance Sheets. If Total assets on line 25, column (B) are \$2,500,000 or more, file Form 990 instead of Form 990-EZ.

(See the instructions for Part II.)

	(A) Beginning of year	(B) End of year
22 Cash, savings, and investments	119,795.	80,546.
23 Land and buildings	1,100.	0.
24 Other assets (describe ▶)		
25 Total assets	120,895.	80,546.
26 Total liabilities (describe ▶ ACCOUNTS PAYABLE)	0.	1,181.
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	120,895.	79,365.

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12-17-08

LHA For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990.

Form 990-EZ (2008)

10P

What is the organization's primary exempt purpose? **SEE STATEMENT 4**

Expenses
(Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts; optional for others.)

31a	
32	43,063.

31a	
32	43,063.
e instructions for Part IV)	
Contributions	

[illegible]

Part V Other Information (Note the statement requirements in the instructions for Part VI)

	Yes	No
33 Did the organization engage in any activity not previously reported to the IRS? If "Yes," attach a detailed description of each activity		X
34 Were any changes made to the organizing or governing documents but not reported to the IRS? If "Yes," attach a conformed copy of the changes		X
35 If the organization had income from business activities, such as those reported on lines 2, 6a, and 7a (among others), but not reported on Form 990-T, attach a statement explaining your reason for not reporting the income on Form 990-T.		
a Did the organization have unrelated business gross income of \$1,000 or more or section 6033(e) notice, reporting, and proxy tax requirements?		X
b If "Yes," has it filed a tax return on Form 990-T for this year?	N/A	
36 Was there a liquidation, dissolution, termination, or substantial contraction during the year? If "Yes," complete applicable parts of Sch. N		X
37a Enter amount of political expenditures, direct or indirect, as described in the instructions. ▶ 37a 0.		
b Did the organization file Form 1120-POL for this year?		X
38a Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee or were any such loans made in a prior year and still unpaid at the start of the period covered by this return?		X
b If "Yes," complete Schedule L, Part II and enter the total amount involved 38b N/A		
39 Section 501(c)(7) organizations. Enter:		
a Initiation fees and capital contributions included on line 9 39a N/A		
b Gross receipts, included on line 9, for public use of club facilities 39b N/A		
40a Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 ▶ 0. ; section 4912 ▶ 0. ; section 4955 ▶ 0.		
b Section 501(c)(3) and (4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year or did it become aware of an excess benefit transaction from a prior year? If "Yes," complete Schedule L, Part I		X
c Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 ▶ 0.		
d Enter amount of tax on line 40c reimbursed by the organization ▶ 0.		
e All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T		X
41 List the states with which a copy of this return is filed. ▶ CA, PA, IL, MN, CT, NY		
42a The books are in care of ▶ ORGANIZATION Telephone no. ▶ 717-529-5555 Located at ▶ 38 JOHN DRIVE, KIRKWOOD, PA ZIP + 4 ▶ 17536		
b At any time during the calendar year, did the organization have an interest in or a signature or other authority over a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
If "Yes," enter the name of the foreign country: ▶		
See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts		
c At any time during the calendar year, did the organization maintain an office outside of the U.S.?		X
If "Yes," enter the name of the foreign country: ▶		
43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041 - Check here ▶ <input type="checkbox"/> and enter the amount of tax-exempt interest received or accrued during the tax year ▶ 43 N/A		
44 Did the organization maintain any donor advised funds? If "Yes," Form 990 must be completed instead of Form 990-EZ		X
45 Is any related organization a controlled entity of the organization within the meaning of section 512(b)(13)? If "Yes," Form 990 must be completed instead of Form 990-EZ		X

Part VI Section 501(c)(3) organizations only. All section 501(c)(3) organizations must answer questions 46-49 and complete the tables for lines 50 and 51.

- 46 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I
- 47 Did the organization engage in lobbying activities? If "Yes," complete Schedule C, Part II
- 48 Is the organization operating a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E
- 49a Did the organization make any transfers to an exempt non-charitable related organization?
- b If "Yes," was the related organization(s) a section 527 organization?
- 50 Complete this table for the five highest compensated employees (other than officers, directors, trustees and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

	Yes	No
46		X
47		X
48		X
49a		X
49b		

(a) Name and address of each employee paid more than \$100,000	(b) Title and average hours per week devoted to position	(c) Compensation	(D) Contributions to employee benefit plans & deferred compensation	(E) Expense account and other allowances
NONE				
Total number of other employees paid over \$100,000				

- 51 Complete this table for the five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and address of each independent contractor paid more than \$100,000	(b) Type of service	(c) Compensation
NONE		
Total number of other independent contractors each receiving over \$100,000		

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

Sign Here

Signature of officer: Colleen B. Zak Date: May 15, 2009

Type or print name and title: Colleen B. Zak

Paid Preparer's Use Only

Preparer's signature: Wingant L. Stangor Date: 5/13/09 Check if self-employed: ☐

Firm's name (or yours if self-employed), address, and ZIP + 4: TROUT, EBERSOLE & GROFF, LLP
1705 OREGON PIKE
LANCASTER, PA 17601

EIN: Phone no.: 717-569-2900

May the IRS discuss this return with the preparer shown above? See instructions ☐ Yes ☐ No

Form 990-EZ (2008)

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

To be completed by all section 501(c)(3) organizations and section 4947(a)(1)
nonexempt charitable trusts.

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

OMB No 1545-0047

2008

Open to Public
Inspection

Name of the organization

ARPKD/CHF ALLIANCE

Employer identification number

23-3069557

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: (Please check only **one** organization)

- 1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2 ☐ A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E.)
- 3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**. (Attach Schedule H.)
- 4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: _____
- 5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 ☒ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 ☐ A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9 ☐ An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete the Part III.)
- 10 ☐ An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**. (see instructions)
- 11 ☐ 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 that describes the type of supporting organization and complete lines 11e through 11h.
- a ☐ Type I b ☐ Type II c ☐ Type III - Functionally integrated d ☐ Type III - Other
- e ☐ By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box ☐
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?
- (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
- (ii) A family member of a person described in (i) above?
- (iii) A 35% controlled entity of a person described in (i) or (ii) above?
- h Provide the following information about the organizations the organization supports

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in col. (i) listed in your governing document?		(v) Did you notify the organization in col. (i) of your support?		(vi) Is the organization in col. (i) organized in the U.S.?		(vii) Amount of support
			Yes	No	Yes	No	Yes	No	
Total									

LHA For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule A (Form 990 or 990-EZ) 2008

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.)

Section A. Public Support

Calendar year (or fiscal year beginning in)▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	30,580.	39,386.	62,480.	35,920.	43,153.	211,519.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 - 3	30,580.	39,386.	62,480.	35,920.	43,153.	211,519.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public Support. Subtract line 5 from line 4						211,519.

Section B. Total Support

Calendar year (or fiscal year beginning in)▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
7 Amounts from line 4	30,580.	39,386.	62,480.	35,920.	43,153.	211,519.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources				4,964.	935.	5,899.
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV)						
11 Total support. Add lines 7 through 10						217,418.
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2008 (line 6, column (f) divided by line 11, column (f))	14	97.29 %
15 Public support percentage from 2007 Schedule A, Part IV-A, line 26f	15	%
16a 33 1/3% support test - 2008. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ▶ <input checked="" type="checkbox"/>		
b 33 1/3% support test - 2007. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
17a 10% -facts-and-circumstances test - 2008. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
b 10% -facts-and-circumstances test - 2007. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ▶ <input type="checkbox"/>		

Schedule A (Form 990 or 990-EZ) 2008

Part III Support Schedule for Organizations Described in Section 509(a)(2) (Complete only if you checked the box on line 9 of Part I.)**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(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 - 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 1% of the total of lines 9, 10c, 11, and 12 for the year or \$5,000						
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) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(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 in 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 IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2008 (line 8, column (f) divided by line 13, column (f))	15		%
16 Public support percentage from 2007 Schedule A, Part IV-A, line 27g	16		%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2008 (line 10c, column (f) divided by line 13, column (f))	17		%
18 Investment income percentage from 2007 Schedule A, Part IV-A, line 27h	18		%
19a 33 1/3% support tests - 2008. 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 ▶ <input type="checkbox"/>			
b 33 1/3% support tests - 2007. 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 ▶ <input type="checkbox"/>			
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ▶ <input type="checkbox"/>			

FORM 990-EZ	OTHER EXPENSES	STATEMENT	1
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DESCRIPTION	AMOUNT
OFFICE	5,630.
FUNDRAISING	3,722.
INSURANCE	4,378.
COMMUNICATION	2,883.
CONFERENCES	3,150.
DUES & SUBSCRIPTIONS	260.
DEPRECIATION	1,100.
BANK & PROCESSING FEES	1,118.
TOTAL TO FORM 990-EZ, LINE 16	22,241.

FORM 990-EZ	CASH GRANTS AND ALLOCATIONS	STATEMENT	2
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CLASS OF ACTIVITY/DONEE'S NAME AND ADDRESS	DONEE'S RELATIONSHIP	AMOUNT
RESEARCH GRANT DR REBECCA WELLS-UNIVERSITY OF PA UNIVERSITY OF PA PA	NONE	25,000.
TOTAL INCLUDED ON FORM 990-EZ, LINE 10		25,000.

FORM 990-EZ

INFORMATION REGARDING TRANSFERS
ASSOCIATED WITH PERSONAL BENEFIT CONTRACTS

STATEMENT 3

- A) DID THE ORGANIZATION, DURING THE YEAR, RECEIVE ANY FUNDS,
DIRECTLY OR INDIRECTLY, TO PAY PREMIUMS ON A PERSONAL
BENEFIT CONTRACT? [] YES [X] NO
- B) DID THE ORGANIZATION, DURING THE YEAR, PAY PREMIUMS,
DIRECTLY OR INDIRECTLY, ON A PERSONAL BENEFIT CONTRACT? . . [] YES [X] NO

ORGANIZATION'S PURPOSE IS TO EDUCATE, ADVOCATE, SUPPORT AND ADVANCE RESEARCH SPECIFIC TO ARPkd/CHF. THE ULTIMATE PURPOSE IS TO IMPROVE THE LIVES OF THOSE AFFECTED WITH ARPkd/CHF.