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Form **990-EZ**Department of the Treasury
Internal Revenue Service**Short Form**
Return of Organization Exempt From Income TaxUnder section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code
(except black lung benefit trust or private foundation)

▶ 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 \$500,000 and total assets less than \$1,250,000 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.

OMB No 1545-1150

2009**Open to Public
Inspection****A** For the 2009 calendar year, or tax year beginning

, 2009, and ending

, 20

B Check if applicable:

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

Please
use IRS
label or
print or
type.
See
Specific
Instruc-
tions.**C** Name of organization**Alagille Syndrome Alliance**

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

Room/suite

10500 SW Starr Dr

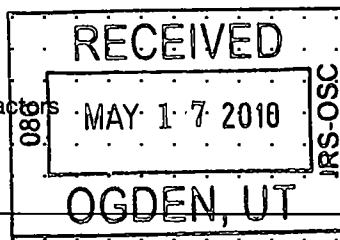
City or town, state or country, and ZIP + 4

Tualatin, OR 97062-8411**D** Employer identification number**93-1243619****E** Telephone number**503-885-0455****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) ▶ **modified cash****I** Website: ▶ **alagille.org****J** Tax-exempt status (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 Form 990-EZ or Form 990 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 \$500,000 or more, file Form 990 instead of Form 990-EZ. ▶ \$ **52242****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	47870
	2	Program service revenue including government fees and contracts	2	0
	3	Membership dues and assessments	3	0
	4	Investment income	4	387
	5a	Gross amount from sale of assets other than inventory	5a	3552
	b	Less: cost or other basis and sales expenses	5b	3540
	c	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a)	5c	12
	6	Special events and activities (complete applicable parts of Schedule G). If any amount is from gaming, check here ☐		
	a	Gross revenue (not including \$ 676 of contributions reported on line 1)	6a	4337
	b	Less: direct expenses other than fundraising expenses	6b	4337
c	Net income or (loss) from special events and activities (Subtract line 6b from line 6a)	6c	0	
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	0	
8	Other revenue (describe ▶)	8	0	
9	Total revenue. Add lines 1, 2, 3, 4, 5c, 6c, 7c, and 8	9	48269	
Expenses	10	Grants and similar amounts paid (attach schedule)	10	0
	11	Benefits paid to or for members	11	0
	12	Salaries, other compensation, and employee benefits	12	0
	13	Professional fees and other payments to independent contractors	13	
	14	Occupancy, rent, utilities, and maintenance	14	1146
	15	Printing, publications, postage, and shipping	15	6985
	16	Other expenses (describe ▶ sched attached)	16	20432
17	Total expenses. Add lines 10 through 16	17	28563	
Net Assets	18	Excess or (deficit) for the year (Subtract line 17 from line 9)	18	19706
	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	77357
	20	Other changes in net assets or fund balances (attach explanation)	20	0
	21	Net assets or fund balances at end of year. Combine lines 18 through 20	21	97063

**Part II Balance Sheets.** If Total assets on line 25, column (B) are \$1,250,000 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	77925	97524
23 Land and buildings	n/a	n/a
24 Other assets (describe ▶)	n/a	n/a
25 Total assets	77925	97524
26 Total liabilities (describe ▶)	568	462
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	77357	97063

For Privacy Act and Paperwork Reduction Act Notice, see the separate instructions.

Cat No 106421

Form **990-EZ** (2009)

SCANNED JUL 02 2010

Part III Statement of Program Service Accomplishments (See the instructions for Part III.)

What is the organization's primary exempt purpose?	To network & distribute info. about Alagille Syndrome
Describe what was achieved in carrying out the organization's exempt purposes. In a clear and concise manner, describe the services provided, the number of persons benefited, and other relevant information for each program title.	

Expenses

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

28	Support Network (see attached schedule)		
	(Grants \$) If this amount includes foreign grants, check here ► ☐	28a	5943
29	Family Gatherings (see attached schedule)		
	(Grants \$) If this amount includes foreign grants, check here ► ☐	29a	4526
30	Gather and Distribute Information and Increase Public Awareness (see attached schedule)		
	(Grants \$) If this amount includes foreign grants, check here ► ☐	30a	6036
31	Other program services (attach schedule)		
	(Grants \$) If this amount includes foreign grants, check here ► ☐	31a	
32	Total program service expenses (add lines 28a through 31a)	32	16505

Part IV	List of Officers, Directors, Trustees, and Key Employees. List each one even if not compensated. (See the instructions for Part IV.)
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[illegible]

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

	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	33	✓
34 Were any changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the changes	34	✓
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 why the organization did not report the income on Form 990-T.		
a Did the organization have unrelated business gross income of \$1,000 or more or was it subject to section 6033(e) notice, reporting, and proxy tax requirements?	35a	✓
b If "Yes," has it filed a tax return on Form 990-T for this year?	35b	
36 Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N	36	✓
37a Enter amount of political expenditures, direct or indirect, as described in the instructions. ▶ 37a		
b Did the organization file Form 1120-POL for this year?	37b	✓
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 outstanding at the end of the period covered by this return?	38a	✓
b If "Yes," complete Schedule L, Part II and enter the total amount involved 38b		
39 Section 501(c)(7) organizations. Enter:		
a Initiation fees and capital contributions included on line 9 39a		
b Gross receipts, included on line 9, for public use of club facilities 39b		
40a Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 ▶ <u>0</u> ; section 4912 ▶ <u>0</u> ; section 4955 ▶ <u>0</u>		
b Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year or is it 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? If "Yes," complete Schedule L, Part I	40b	✓
c Section 501(c)(3) and 501(c)(4) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 ▶ <u>0</u>		
d Section 501(c)(3) and 501(c)(4) organizations. Enter amount of tax on line 40c reimbursed by the organization ▶ <u>0</u>		
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.	40e	✓
41 List the states with which a copy of this return is filed. ▶ Oregon		
42a The organization's books are in care of ▶ Cindy L. Hahn Telephone no. ▶ 503-885-0455 Located at ▶ 10500 SW Starr Drive, Tualatin, OR ZIP + 4 ▶ 97062-8411		
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)?	42b	✓
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.?	42c	✓
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 ▶ ☐ and enter the amount of tax-exempt interest received or accrued during the tax year ▶ 43		
44 Did the organization maintain any donor advised funds? If "Yes," Form 990 must be completed instead of Form 990-EZ	44	✓
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	45	✓

Part VI **Section 501(c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts only.** All section 501(c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts must answer questions 46-49b 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. **Yes** **No**
- 47** Did the organization engage in lobbying activities? If "Yes," complete Schedule C, Part II. **46** **47** **48** **49a** **49b**
- 48** Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E. **46** **47** **48** **49a** **49b**
- 49a** Did the organization make any transfers to an exempt non-charitable related organization? **46** **47** **48** **49a** **49b**
- b** If "Yes," was the related organization a section 527 organization? **46** **47** **48** **49a** **49b**
- 50** Complete this table for the organization's 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."

(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				

f Total number of other employees paid over \$100,000 ▶

- 51** Complete this table for the organization's 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		

d Total number of other independent contractors each receiving over \$100,000 ▶

Sign Here	Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.						
	 Signature of officer Cindy L. Hahn, President Type or print name and title Date 5-11-10						
	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 40%; padding: 5px;"> Paid Preparer's Use Only Preparer's signature ▶ Firm's name (or yours if self-employed), address, and ZIP + 4 ▶ </td> <td style="width: 10%; padding: 5px;">Date</td> <td style="width: 10%; padding: 5px;"> Check if self-employed ☐ </td> <td style="width: 40%; padding: 5px;"> Preparer's identifying number (See instructions) EIN ▶ Phone no ▶ </td> </tr> </table>				Paid Preparer's Use Only Preparer's signature ▶ Firm's name (or yours if self-employed), address, and ZIP + 4 ▶	Date	Check if self-employed ☐
Paid Preparer's Use Only Preparer's signature ▶ Firm's name (or yours if self-employed), address, and ZIP + 4 ▶	Date	Check if self-employed ☐	Preparer's identifying number (See instructions) EIN ▶ Phone no ▶				

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

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) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	41011	33655	21606	78904	47870	223046
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf	0	0	0	0	0	0
3 The value of services or facilities furnished by a governmental unit to the organization without charge	0	0	0	0	0	0
4 Total. Add lines 1 through 3	41011	33655	21606	78904	47870	223046
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)						40931
6 Public support. Subtract line 5 from line 4.						182115

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4	41011	33655	21606	78904	47870	223046
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	61	196	2312	1476	387	4432
9 Net income from unrelated business activities, whether or not the business is regularly carried on	0	0	0	0	0	0
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	0	0	0	0	0	0
11 Total support. Add lines 7 through 10						227478
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 ☐						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2009 (line 6, column (f) divided by line 11, column (f))	14	80 %
15 Public support percentage from 2008 Schedule A, Part II, line 14	15	76 %
16a 33 1/3 % support test—2009. 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 ☒		
b 33 1/3 % support test—2008. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3 % or more, check this box and stop here. The organization qualifies as a publicly supported organization ☐		
17a 10%-facts-and-circumstances test—2009. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ☐		
b 10%-facts-and-circumstances test—2008. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ☐		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ► ☐		

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

(Complete only if you checked the box on line 9 of Part I.)

N/A

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(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) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(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 ☐						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2009 (line 8, column (f) divided by line 13, column (f))	15	%
16 Public support percentage from 2008 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2009 (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from 2008 Schedule A, Part III, line 17	18	%

19a 33⅓% support tests—2009. If the organization did not check the box on line 14, and line 15 is more than 33⅓%, and line 17 is not more than 33⅓%, check this box and **stop here**. The organization qualifies as a publicly supported organization ► ☐

b 33⅓% support tests—2008. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33⅓%, and line 18 is not more than 33⅓%, 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

Supplemental Information. Complete this part to provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Provide any other additional information. See instructions.

N/A

Alagille Syndrome Alliance
FEI #93-1243619
Calendar Year 2009

Form 990EZ

Part I - Revenue, Expenses and Changes in Net Assets or Fund Balances

Line

16	Other Expenses:	
	Charitable donations	\$ 5
	Computer supplies	1,547
	Finance charges	926
	Insurance	991
	Membership dues - organizations	430
	Office supplies	945
	Promotional	5,691
	Training	334
	Conference, gatherings, meetings	9,460
	Taxes and licenses	103
		<u>\$ 20,432</u>

Alagille Syndrome Alliance
FEI # 93-1243619
Calendar Year 2009

Form 990EZ

Part III: Statement of Program Service Accomplishments

The purpose of the Alagille Syndrome Alliance is to serve as the main networking resource and source of information for people with Alagille Syndrome, Their families, friends and health care providers. The Alliance also is dedicated to increasing public awareness of Alagille Syndrome and supporting research efforts on behalf of the AGS Community.

- | | | |
|-----|---|---------------|
| 28 | Support Network. Goal: To provide a support network for people whose lives have been touched directly or indirectly by AGS. Accomplishments: Continued to serve AGS families via telephone, email, web site and newsletter. The Alliance web site is visited numerous times a day by people interested in learning more about AGS or wanting to reach out to others. | |
| a. | Expenses | 5,943 |
| | | |
| 29 | Family Gatherings. Goal: To provide a forum which enables AGS families to meet one another on a regular basis for mutual support and sharing of current information on AGS. Accomplishments: Hosted Symposium in San Francisco, CA, in summer 2008. Attended by approx. xxx people, including families, speakers and health care professionals attended. Hosting regional gatherings for families. | |
| a. | Expenses | 4,526 |
| | | |
| 30. | Gather and Distribute Information, and Increase Public Awareness. Goal: To gather and distribute information about AGS, research studies, and helpful services to AGS families, friends, and health care providers. To increase public awareness of AGS. Accomplishments: Published and distributed a quarterly newsletter to 650 individuals, families, etc. | |
| a. | Expenses | <u>6,036</u> |
| | | |
| 32 | Total program service expenses | <u>16,505</u> |

Alagille Syndrome Alliance
FEI # 93-1243619
Calendar Year 2009

Form 990EZ

Part IV: List of Directors, Trustees, and Key Employees

(A)	(B)	(C)	(D)	(E)
Cindy L. Hahn 10500 SW Starr Drive Tualatin, OR 97062	President 20-25 hrs	0	0	0
Chris J. Hahn 10500 SW Starr Drive Tualatin, OR 97062	Director <5 hours	0	0	0
Erik K. Luxhoj 1517 S Clara St Appleton, WI 54915	Director 5-10 hours	0	0	0
Joseph M. Anderson 120 S. 400 W Brigham City, UT 84302	Director <5 hours	0	0	0
Elizabeth A Caldwell 100 Union Street Cardington, OH 43315	Director <5 hours	0	0	0
Richard E. Caldwell 100 Union Street Cardington, OH 43315	Director <5 hours	0	0	0
Patricia H. Everett 550 West Magnolia Circle Alpharetta, GA 30005	Director <5 hours	0	0	0
Wanda L. Sheppard 3029 Granada Place Plano, TX 75023	Director <5 hours	0	0	0

Part V: Other Information

Line 35 – The gross revenue reported on line 6a Part 1 is from a golf tournament co-hosted by the Alagille Syndrome Alliance. This is not an activity we regularly carry on and therefore does not require reporting on Form 990-T.