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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

THE FOUNDATION WAS CREATED TO EDUCATE AND SUPPORT PATIENTS AND FAMILIES THAT HAVE BEEN AFFECTED BY THIS GENETIC KIDNEY DISEASE WITH A GOAL OF FUNDING RESEARCH, TO FIND MORE EFFECTIVE TREATMENT PROTOCOLS AND TO ULTIMATELY FIND A CURE

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 \$ 123,500 including grants of \$ 123,500) (Revenue \$)

AWARDED RESEARCH FUNDING TO DR OLIVER GROSS OF THE UNIVERSITY MEDICAL CENTER GOTTINGEN, GERMANY FOR HIS ONE-YEAR STUDY THAT WILL EVALUATE ANTIMICRORNA-21 IN REDUCING RENAL SCARRING AND PROMOTING KIDNEY FUNCTION IN ALPORT PATIENTS AND DR CLIFFORD KASHTAN, UNIVERSITY OF MINNESOTA A MEDICAL FOUNDATION FOR CONTINURED SUPPORT OF THE ALPORT SYNDROME TREATMENTS AND OUTCOMES REGISTRY

4b

(Code) (Expenses \$ 27,618 including grants of \$) (Revenue \$)

CONDUCTED AN INTERNATIONAL SYMPOSIUM ON ALPORT SYNDROME AT THE INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION 2013 CONGRESS IN SHANGHAI, CHINA OVER 200 PHYSICIANS AND RESEARCHERS ATTENDED THE SYMPOSIUM IN ADDITION ASF PROVIDED INFORMATION ON ALPORT SYNDROME TO THE 1200 CONGRESS ATTENDEES ALSO PROVIDED FINANCIAL SUPPORT FOR US BASED RESEARCHERS TO ATTEND THE INTERNATIONAL WORKSHOP ON ALPORT SYNDROME HELD AT OXFORD UNIVERSITY, UNITED KINGDOM

4c

(Code) (Expenses \$ 26,957 including grants of \$) (Revenue \$)

ATTENDED AND EXHIBITED AT THE AMERICAN SOCIETY OF NEPHROLOGY KIDNEY WEEK IN ATLANTA, GEORGIA IN NOVEMBER 2013 INCREASING AWARENESS AND DISTRIBUTING EDUCATIONAL INFORMATION TO THE OVER 12,000 MEDICAL AND RESEARCH COMMUNITY ATTENDEES MET WITH MEMBERS OF ASF MEDICAL ADVISORY COMMITTEE TO DISCUSS 2013 PERFORMANCE AND PLANS FOR 2014 HELD MEETINGS WITH BOTH NATIONAL AND INTERNATIONAL RESEARCH COMMUNITY TO DISCUSS TRENDS AND NEW POSSIBLE OPPORTUNITIES FOR RESEARCH HELD A REGIONAL FAMILY MEETING FOR OVER 50 PARTICIPANTS WITH MEDICAL EXPERTS FROM THE US AND GERMANY

4d

Other program services (Describe in Schedule O)

(Expenses \$ 13,950 including grants of \$ 3,750) (Revenue \$)

4e

Total program service expenses

192,025

Form 990 (2013)

Part IV

Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A 	1 Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	2 Yes	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3	No
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II	4	No
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5	No
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6	No
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7	No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8	No
9 Did the organization report an amount in Part X, line 21 for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV	9	No
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V	10	No
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.	11a	No
b Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b	No
c Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c	No
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX	11d	No
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	No
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X	11f	No
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a	No
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b	No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV 	14b Yes	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV 	15 Yes	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16	No
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I (see instructions)	17	No
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II 	18 Yes	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	19	No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	Yes	
22	Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	Yes	
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>	23		No
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>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		No
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		No
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		No
25a	Section 501(c)(3) and 501(c)(4) 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>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If so, complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> . . .	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		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>	32		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? <i>If "Yes," complete Schedule R, Part I</i>	33		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>	34		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	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>	35b		
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>	36		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>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O	38	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			5	
1b Enter the number of Forms W-2G included in line 1a Enter -0- if not applicable			0	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?			1c	
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	0
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	
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)?			4a	No
b If "Yes," enter the name of the foreign country See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts				
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	No
b If "Yes," did the organization notify the donor of the value of the goods or services provided?			7b	
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 and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?			8	
9 Sponsoring organizations maintaining donor advised funds.				
a Did the organization make any taxable distributions under section 4966?			9a	
b Did the 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?			12a	
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? Note. See the instructions for additional information the organization must report on Schedule O			13a	
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	

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

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

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

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

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed▶UT , PA , NY , NJ , NH , KY , IL , FL , AZ
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. ☐ Own website ☐ Another's website ☒ Upon request ☐ Other (explain in Schedule O)
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, physical address, and telephone number of the person who possesses the books and records of the organization ▶STANLEY SILVER30042 N 77TH PLACE SCOTTSDALE,AZ 85266 (480) 473-3209

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

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** key employees, if any. See instructions for definition of "key employee."

- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations

- List all of the organization's **former** officers, key employees, 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

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

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

[illegible]

Part VII

[illegible]

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>	3	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>	4	No
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>	5	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 ►

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 Similar Amounts	1a	Federated campaigns	1a			
	b	Membership dues	1b			
	c	Fundraising events	1c	40,521		
	d	Related organizations	1d			
	e	Government grants (contributions)	1e			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	165,829		
	g	Noncash contributions included in lines 1a-1f \$				
	h	Total. Add lines 1a-1f		206,350		
Program Service Revenue			Business Code			
	2a					
	b					
	c					
	d					
	e					
	f	All other program service revenue				
	g	Total. Add lines 2a-2f				
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		286		286
	4	Income from investment of tax-exempt bond proceeds				
	5	Royalties				
			(i) Real	(ii) Personal		
	6a	Gross rents				
	b	Less rental expenses				
	c	Rental income or (loss)				
	d	Net rental income or (loss)				
			(i) Securities	(ii) Other		
	7a	Gross amount from sales of assets other than inventory				
	b	Less cost or other basis and sales expenses				
	c	Gain or (loss)				
	d	Net gain or (loss)				
	8a	Gross income from fundraising events (not including \$ 40,521 of contributions reported on line 1c) See Part IV, line 18	a			
	b	Less direct expenses	b	5,264		
	c	Net income or (loss) from fundraising events		-5,264		-5,264
	9a	Gross income from gaming activities See Part IV, line 19	a			
	b	Less direct expenses	b			
	c	Net income or (loss) from gaming activities				
	10a	Gross sales of inventory, less returns and allowances	a			
	b	Less cost of goods sold	b			
	c	Net income or (loss) from sales of inventory				
	Miscellaneous Revenue		Business Code			
11a	UNREIMBURSED OFFICER EXPENSES	900099	5,437	5,437		
b						
c						
d	All other revenue					
e	Total. Add lines 11a-11d		5,437			
12	Total revenue. See Instructions		206,809	5,437	-4,978	

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 governments and organizations in the United States. See Part IV, line 21.	123,500	123,500		
2	Grants and other assistance to individuals in the United States. See Part IV, line 22.	3,750	3,750		
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16.	0			
4	Benefits paid to or for members.	0			
5	Compensation of current officers, directors, trustees, and key employees.	0			
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).	0			
7	Other salaries and wages.	0			
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).	0			
9	Other employee benefits.	0			
10	Payroll taxes.	0			
11	Fees for services (non-employees):				
a	Management.	0			
b	Legal.	0			
c	Accounting.	2,772		2,772	
d	Lobbying.	0			
e	Professional fundraising services. See Part IV, line 17.				
f	Investment management fees.	1,121			1,121
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	22,636	8,318	8,318	6,000
12	Advertising and promotion.	749			749
13	Office expenses.	6,613	5,691	764	158
14	Information technology.	6,246	5,618	628	
15	Royalties.	0			
16	Occupancy.	0			
17	Travel.	10,271	10,271		
18	Payments of travel or entertainment expenses for any federal, state, or local public officials.	0			
19	Conferences, conventions, and meetings.	12,811	12,811		
20	Interest.	0			
21	Payments to affiliates.	0			
22	Depreciation, depletion, and amortization.	0			
23	Insurance.	2,243	725	1,518	
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	BANK AND CREDIT CARD FEE	2,620	1,986	444	190
b	PROGRAM EXHIBIT MATERIALS, SUPPLIES	23,095	19,345		3,750
c	REGISTRATION FEES	785	10		775
d					
e	All other expenses	0			
25	Total functional expenses. Add lines 1 through 24e.	219,212	192,025	14,444	12,743
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 ☐ 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 X

				(A)		(B)
				Beginning of year		End of year
Assets	1	Cash—non-interest-bearing		239,120	1	226,431
	2	Savings and temporary cash investments		125,856	2	126,142
	3	Pledges and grants receivable, net			3	
	4	Accounts receivable, net			4	
	5	Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L.			5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions). Complete Part II of Schedule L.			6	
	7	Notes and loans receivable, net			7	
	8	Inventories for sale or use			8	
	9	Prepaid expenses and deferred charges		903	9	903
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D.	10a		10c	
	b	Less: accumulated depreciation	10b			
	11	Investments—publicly traded securities			11	
	12	Investments—other securities. See Part IV, line 11.			12	
	13	Investments—program-related. See Part IV, line 11.			13	
	14	Intangible assets			14	
	15	Other assets. See Part IV, line 11.			15	
	16	Total assets. Add lines 1 through 15 (must equal line 34).		365,879	16	353,476
Liabilities	17	Accounts payable and accrued expenses			17	
	18	Grants payable			18	
	19	Deferred revenue			19	
	20	Tax-exempt bond liabilities			20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D.			21	
	22	Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L.			22	
	23	Secured mortgages and notes payable to unrelated third parties.			23	
	24	Unsecured notes and loans payable to unrelated third parties.			24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17–24). Complete Part X of Schedule D.			25	
	26	Total liabilities. Add lines 17 through 25.		0	26	0
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here ☒ and complete lines 27 through 29, and lines 33 and 34.					
	27	Unrestricted net assets		365,879	27	353,476
	28	Temporarily restricted net assets			28	
	29	Permanently restricted net assets			29	
	Organizations that do not follow SFAS 117 (ASC 958), check here ☐ and complete lines 30 through 34.					
	30	Capital stock or trust principal, or current funds			30	
	31	Paid-in or capital surplus, or land, building or equipment fund			31	
	32	Retained earnings, endowment, accumulated income, or other funds			32	
	33	Total net assets or fund balances.		365,879	33	353,476
	34	Total liabilities and net assets/fund balances.		365,879	34	353,476

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	206,809
2	Total expenses (must equal Part IX, column (A), line 25)	2	219,212
3	Revenue less expenses Subtract line 2 from line 1	3	-12,403
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	365,879
5	Net unrealized gains (losses) on investments	5	
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	
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	353,476

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 ☐ Cash ☒ Accrual ☐ Other If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? 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 ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	Yes	
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 ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		No
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		

SCHEDULE A

(Form 990 or 990EZ)

Department of the
Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

▶ **Attach to Form 990 or Form 990-EZ.** ▶ **See separate instructions.**
▶ **Information about Schedule A (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990*.**

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization ALPORT SYNDROME FOUNDATION INC	Employer identification number 20-8237159
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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 11, check only one box)

1	☐	A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i).
2	☐	A school described in section 170(b)(1)(A)(ii). (Attach Schedule E)
3	☐	A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii).
4	☐	A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state _____
5	☐	An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II)
6	☐	A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v).
7	☒	An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II)
8	☐	A community trust described in section 170(b)(1)(A)(vi) (Complete Part II)
9	☐	An organization that normally receives (1) more than 33 ¹ / ₃ % of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 ¹ / ₃ % of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See section 509(a)(2). (Complete Part III)
10	☐	An organization organized and operated exclusively to test for public safety See section 509(a)(4).
11	☐	An organization organized and operated exclusively for the benefit of, to perform the functions of, or 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 - Non-functionally integrated
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 supported organization(s)

	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 monetary support
			Yes	No	Yes	No	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 fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	67,467	87,529	197,405	216,610	206,350	775,361
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	67,467	87,529	197,405	216,610	206,350	775,361
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)						57,641
6 Public support. Subtract line 5 from line 4						717,720

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4	67,467	87,529	197,405	216,610	206,350	775,361
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	351	216	313	327	286	1,493
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)						776,854
12 Gross receipts from related activities, etc (see instructions)					12	273,974
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						▶

Section C. Computation of Public Support Percentage

14 Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f))	14	92 390 %
15 Public support percentage for 2012 Schedule A, Part II, line 14	15	95 000 %
16a 33 1/3% support test—2013. 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—2012. 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—2013. 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—2012. 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 IIISupport Schedule for Organizations Described in Section 509(a)(2)
(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(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) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(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 501(c)(3) organization, check this box and stop here ▶						

Section C. Computation of Public Support Percentage		
15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f))	15	0 %
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f))	17	0 %
18 Investment income percentage from 2012 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2013. 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—2012. 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

Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test		
Return Reference	Explanation	

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.

► Attach to Form 990. ► See separate instructions.

► Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization
ALPORT SYNDROME FOUNDATION INC

Employer identification number
20-8237159

Part I General Information on Activities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 14b.

- 1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ Yes ☐ No
- 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3 Activites per Region (The following Part I, line 3 table can be duplicated if additional space is needed)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
East Asia and the Pacific			SYMPOSIUM ON ALPORT SYNDROME	RESEARCH SYMPOSIUM	20,565
3a Sub-total					20,565
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					20,565

Part II

Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			Europe	RESEARCH	98,500	WIRE TRANSFER			

- 2
- Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter ▶
- 1
- 3
- Enter total number of other organizations or entities ▶

Part III

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
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Part IV Foreign Forms

- 1

Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)*

☐

Yes

☒

No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)*

☐

Yes

☒

No
- 3

Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)*

☐

Yes

☒

No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)*

☐

Yes

☒

No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships. (see Instructions for Form 8865)*

☐

Yes

☒

No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report (see Instructions for Form 5713).*

☐

Yes

☒

No

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		ARIZONA 5K RACE (event type)	(event type)	(total number)	(add col (a) through col (c))
Revenue	1	Gross receipts	40,521		40,521
	2	Less Contributions	40,521		40,521
	3	Gross income (line 1 minus line 2)			
Direct Expenses	4	Cash prizes			
	5	Noncash prizes	750		750
	6	Rent/facility costs	500		500
	7	Food and beverages			
	8	Entertainment	452		452
	9	Other direct expenses	3,562		3,562
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶			
	11	Net income summary Subtract line 10 from line 3, column (d) ▶			

Part III Gaming. Complete if the organization answered "Yes" to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
Revenue	1	Gross revenue			
	2	Cash prizes			
Direct Expenses	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	
	7	Direct expense summary Add lines 2 through 5 in column (d) ▶			
	8	Net gaming income summary Subtract line 7 from line 1, column (d) ▶			

9 Enter the state(s) in which the organization operates gaming activities _____

a Is the organization licensed to operate gaming activities in each of these states? ☐ Yes ☐ No

b If "No," explain _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? ☐ Yes ☐ No

b If "Yes," explain _____

Does the organization operate gaming activities with nonmembers? ☐ **Yes** ☐ **No**

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? ☐ **Yes** ☐ **No**

13 Indicate the percentage of gaming activity operated in

a The organization's facility	13a	%
b An outside facility	13b	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records

Name ▶

Address ▶

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? ☐ **Yes** ☐ **No**

b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ _____ and the amount of gaming revenue retained by the third party ▶ \$ _____

c If "Yes," enter name and address of the third party

Name ▶

Address ▶

16 Gaming manager information

Name ▶

Gaming manager compensation ▶ \$ _____

Description of services provided ▶

☐ Director/officer ☐ Employee ☐ Independent contractor

17 Mandatory distributions

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ **Yes** ☐ **No**

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV **Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also complete this part to provide any additional information (see instructions).

Return Reference	Explanation
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Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Name of the organization
ALPORT SYNDROME FOUNDATION INC

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

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

▶ Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

Employer identification number
20-8237159

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 Governments and Organizations in the United States. Complete if the organization answered "Yes" to 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 Code 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 non-cash assistance	(h) Purpose of grant or assistance
(1) UNIVERSITY OF MN MEDICAL FOUNDATION 200 OAK STREET SE SUITE 500 MINNEAPOLIS, MN 554552010	41-6042488	501 C 3	25,000				RESEARCH

2

Enter total number of section 501(c)(3) and government organizations listed in the line 1 table

1

3

Enter total number of other organizations listed in the line 1 table

Part III

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to 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 non-cash assistance	(e)Method of valuation (book, FMV, appraisal, other)	(f)Description of non-cash assistance
(1) EDUCATION RESEARCH	5	3,750			

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 1	FOR RESEARCH FUNDING, ASF USES AN APPLICATION PROCESS ALONG WITH A PANEL OF OUTSIDE REVIEWERS WHICH EVALUATE GRANT APPLICATIONS ON THE SPECIFIC AIMS OF THE PROJECT, THE PROJECTS BACKGROUND AND SIGNIFICANCE, AND THE PROJECTS RESEARCH DESIGN AND METHODS
Part I Line 2	REPORTING REQUIREMENTS - WITHIN 60 DAYS OF THE END OF THE FUNDING PERIOD, IT IS REQUIRED THAT A TYPE-WRITTEN REPORT BY THE PRINCIPAL INVESTIGATOR ON THE RESEARCH THAT RESULTED FROM THE ASF FUNDING SUMMARY WHICH CAN BE PUBLISHED BY ASF AS IS OR IN EDITED FORM MUST BE SUBMITTED IF THE FUNDING IS FOR MORE THAN A ONE-YEAR PERIOD, THEN A TYPE-WRITTEN PROGRESS REPORT MUST BE ISSUED BY THE PRINCIPAL INVESTIGATOR AT THE END OF EACH YEAR ON THE FUNDING COMMENCEMENT DATE ANNIVERSARY AND SENT TO ASF
Part I Line 2	ACCOUNTING REQUIREMENTS - A FINAL DETAILED ACCOUNTING OF THE FUNDS SPENT IS REQUIRED TO BE SENT TO ASF WITHIN 60 DAYS OF THE END OF THE FUNDING PERIOD IF THE FUNDING PERIOD IS LONGER THAN ONE YEAR, THEN ANNUAL FINANCIAL REPORTS MUST BE FILED WITH ASF ON THE FUNDING COMMENCEMENT DATE ANNIVERSARY AT THE END OF THE FUNDING PERIOD, ANY UNUSED FUNDS MUST BE RETURNED TO ASF, UNLESS A LETTER EXPLAINING THE SITUATION AND REQUESTING AN EXTENSION OF THE FUNDING PERIOD WITHOUT ADDITIONAL FUNDS IS SUBMITTED AT LEAST 90 DAYS PRIOR TO THE END OF THE FUNDING PERIOD AND APPROVED BY ASF
Part III Line 1	EACH YEAR ASF SPONSORS THE PAUL SILVER TRIBUTE AWARD FOR STUDENTS AND YOUNG ADULTS WITH ALPORT SYNDROME APPLICANTS ARE EVALUATED BASED ON AN ESSAY AND OUTSIDE RECOMMENDATIONS AND ON THE POTENTIAL IMPACT OF THE AWARD THE AWARD CAN BE USED FOR EDUCATION, TO COMPLETE A PROJECT, OR PURSUE AN ACTIVITY THAT WILL ENHANCE THE APPLICANTS LIFE

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990 or 990-EZ.
▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at
www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization ALPORT SYNDROME FOUNDATION INC	Employer identification number 20-8237159
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990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part III, Line 4d	Program Service Expenses 10,200, Grants and allocations 0, Revenue 0 CONTINUED TO INCREASE OUTREACH AND AWARENESS TO THE PATIENT COMMUNITY THROUGH UPGRADES TO THE FOUNDATION WEBSITE, EMAIL CAPACITIES, INCREASED MAILINGS AND FOUNDATION FORUM INCREASED THE USE OF SOCIAL MEDIA WITH THE USE OF BOTH FACEBOOK AND TWITTER HELD VARIOUS MEETINGS WITH LOCAL BUSINESS LEADERS
Form 990, Part III, Line 4d	Program Service Expenses 3,750, Grants and allocations 3,750, Revenue 0 AWARDED FIVE STUDENTS WITH THE PAUL SILVER TRIBUTE AWARD IN A PAY IT FORWARD MANNER TO ENCOURAGE PERSONAL GROWTH AND A SENSE OF EMPOWERMENT
Form 990, Part VI, Section A, Line 2	PRESIDENT SHARON LAGAS, AND TREASURER STANLEY SILVER, ARE RELATED AS DEFINED BY THE IRS DEFINITION OF RELATIVE
Form 990, Part VI, Section B, Line 11	THE TREASURER OF THE ORGANIZATION DISTRIBUTES A PDF COPY OF 990 RETURN TO ALL BOARD MEMBERS FOR A REVIEW AND COMMENT PRIOR TO BEING FILED AT THE FIRST MEETING OF THE BOARD FOLLOWING THE FILING OF THE 990 WITH THE IRS, THE COMPLETE FORM 990 IS PRESENTED TO THE BOARD BY THE ORGANIZATIONS LEAD OFFICERS WITH RESPONSIBILITY OVER THE FORM 990S REVIEW THEREAFTER, QUESTIONS ARE TAKEN AND THE FORM, ITS PREPARATION, AND ITS PUBLIC RELATION IMPACT IS DISCUSSED
Form 990, Part VI, Section B, Line 12C	AT EACH BOARD AND COMMITTEE MEETING, IF THERE IS A DISCUSSION OF SELECTING OR ENGAGING A VENDOR OR SERVICE PROVIDER, ALL IN ATTENDANCE ARE ASKED TO RECUSE THEMSELVES FROM THIS DISCUSSION IF THERE COULD BE A PERCEIVED CONFLICT ANNUALLY, THE ORGANIZATION REVIEWS AND DISCUSSES THE CONFLICT OF INTEREST POLICY AND REQUESTS THAT EACH BOARD MEMBER LIST AND ACKNOWLEDGE ANY KNOWN CONFLICTS
Form 990, Part VI, Section B, Line 15 A B	THE ORGANIZATION DOES NOT CURRENTLY HAVE ANY PAID OFFICERS OR EMPLOYEES HOWEVER, A COMPENSATION POLICY IS IN PLACE THAT WOULD REQUIRE THE BOARD AS WHOLE, OR THE EXECUTIVE COMMITTEE TO REVIEW THE COMPENSATION FOR ALL OFFICERS OR KEY EMPLOYEES BY COMPARING THEIR COMPENSATION TO THE COMPENSATION OF INDIVIDUALS IN LIKE POSITIONS , IN COMPARABLE ORGANIZATIONS USING FORMS 990, COMPENSATION STUDIES, AND OTHER AVAILABLE DATA THE BOARD OR COMMITTEE WOULD THEN APPROVE ANY CHANGES TO THE COMPENSATION AGREEMENT BASED ON THIS INFORMATION
Form 990, Part VI, Section C, Line 19	THE ORGANIZATION WILL PROVIDE IN A TIMELY MANNER, COPIES OF ALL GOVERNING DOCUMENTS INCLUDING ITS CONFLICT OF INTEREST POLICIES AND FINANCIAL STATEMENTS WHEN REQUESTED IN WRITING OR IN PERSON
Form 990, Part IX, Section 1, Line 11 G	OTHER FEES FOR SERVICES THE ORGANIZATION HIRED A EVENT CONSULTANT TO ASSIST WITH PROGRAM SYMPOSIUMS AND MEETING LOGISTICS, AND AN ADMINISTRATIVE ASSISTANT