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Part III

Statement of Program Service Accomplishments

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

1

Briefly describe the organization's mission

RESEARCH AND AWARENESS OF

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 \$ 362,749 including grants of \$ 83,091) (Revenue \$ 556,398)

THIS CONSISTS OF VARIOUS FUNDRAISING EVENTS IN WHICH DONATIONS WERE RAISED FOR FUTURE RESEARCH AND AWARENESS THESE EVENTS CONSISTED OF EDUCATING ON CHIARI MALFORMATION, SYRINGOMYELIA AND CEREBROSPINAL FLUID DISORDERS THROUGH DVD'S AND VARIOUS SPEAKERS

4b

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

4c

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

4d

Other program services (Describe in Schedule O)

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

4e

Total program service expenses 362,749

Form 990 (2012)

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 	Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	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		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		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		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 	Yes	
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		No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		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		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		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. 	Yes	
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 	Yes	
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		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		No
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X		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		No
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII 	Yes	
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		No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		No
14a Did the organization maintain an office, employees, or agents outside of the United States?		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		No
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If "Yes," complete Schedule F, Parts II and IV		No
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If "Yes," complete Schedule F, Parts III and IV		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)		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 	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		No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H		No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21		No
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	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 25</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
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		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
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	Was a loan to or by a current or former officer, director, trustee, key employee, highest compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	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	Yes	
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		No
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		
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 to any question in this Part V

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.		
1c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		
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.		
2b	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).	Yes	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		No
3b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O.		
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)?		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?		No
5b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		No
5c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		
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?		No
6b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
7a	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?		No
7b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
7c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		No
7d	If "Yes," indicate the number of Forms 8282 filed during the year.		
7e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		No
7f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		No
7g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		No
7h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		No
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?		No
9	Sponsoring organizations maintaining donor advised funds.		
9a	Did the organization make any taxable distributions under section 4966?		No
9b	Did the organization make a distribution to a donor, donor advisor, or related person?		No
10	Section 501(c)(7) organizations. Enter:		
10a	Initiation fees and capital contributions included on Part VIII, line 12.		
10b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.		
11	Section 501(c)(12) organizations. Enter:		
11a	Gross income from members or shareholders.		
11b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
12b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year.		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13a	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.		
13b	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.		
13c	Enter the amount of reserves on hand.		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		No
14b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.		

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 to any question 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	5	
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			
1b	Enter the number of voting members included in line 1a, above, who are independent	5	
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	No
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
7b	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		
8a	The governing body?	8a	Yes
8b	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	Yes
10b	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	Yes
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	No
11b 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
12b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes
12c	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?		
15a	The organization's CEO, Executive Director, or top management official	15a	Yes
15b	Other officers or key employees of the organization	15b	Yes
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
16b	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	NY
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 DOROTHY POPPE 29 CREST LOOP STATEN ISLAND, NY (718) 966-2593	

Part VII

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

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

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

- 1a Complete this table for all persons required to be listed Report compensation for the calendar year ending with or within the organization's tax year
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation Enter -0- in columns (D), (E), and (F) if no compensation was paid

List all of the organization's **current** key employees, if any See instructions for definition of "key employee "

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) PAUL J FARRELL CHAIRMAN, BD OF DIRECTORS	1 00	X		X				0	0	0
(2) JOE FITZPATRICK V-CHAIRMAN, BD OF DIRECTORS	1 00	X		X				0	0	0
(3) STEVE KRAGRUD TREASURER, BD OF DIRECTORS	1 00	X		X				0	0	0
(4) LORY WATSON DIRECTOR	1 00	X		X				0	0	0
(5) SCOTT GREGERSON DIRECTOR	1 00	X		X				0	0	0
(6) MICHAEL MIKULA CHAIRMAN, BD OF TRUSTEES	1 00	X						0	0	0
(7) DR ROBERT TYRE JONES IV TRUSTEE	1 00	X						0	0	0
(8) EDWIN B JORDAN TRUSTEE	1 00	X						0	0	0
(9) BOB RUMPHREY TRUSTEE	1 00	X						0	0	0
(10) DOUG KINDLON TRUSTEE	1 00	X						0	0	0
(11) SIMON J ARHIBALD PHD TRUSTEE	1 00	X						0	0	0
(12) RICHARD E KUNTZ MD TRUSTEE	1 00	X						0	0	0
(13) SEAN LILIENFELD MD TRUSTEE	1 00	X						0	0	0
(14) LADY TRISH MALLOCH-BROWN TRUSTEE	1 00	X						0	0	0
(15) DOROTHY POPPEE EXECUTIVE DIRECTOR	40	X		X	X	X		103,230		

Part VII

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
1b	Sub-Total									
c	Total from continuation sheets to Part VII, Section A									
d	Total (add lines 1b and 1c)							103,230		

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)	(B)	(C)
Name and business address	Description of services	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 to any question 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, 513, or 514
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns . . .	1a			
	b	Membership dues	1b			
	c	Fundraising events	1c	513,398		
	d	Related organizations	1d			
	e	Government grants (contributions)	1e			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	-260,205		
	g	Noncash contributions included in lines 1a-1f \$				
	h	Total. Add lines 1a-1f		253,193		
Program Service Revenue	2a		Business Code			
	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)	1,748		
4		Income from investment of tax-exempt bond proceeds . .				
5		Royalties				
6a		Gross rents	(i) Real	(ii) Personal		
b		Less rental expenses				
c		Rental income or (loss)				
d		Net rental income or (loss)				
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other		
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 \$ 513,398 of contributions reported on line 1c) See Part IV, line 18	a			
b		Less direct expenses	b			
c		Net income or (loss) from fundraising events . .				
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						
b						
c						
d	All other revenue					
e	Total. Add lines 11a-11d					
12	Total revenue. See Instructions		254,941	1,748		

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 to any question in this Part IX

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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.				
2	Grants and other assistance to individuals in the United States. See Part IV, line 22.	83,091	83,091		
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16.				
4	Benefits paid to or for members.				
5	Compensation of current officers, directors, trustees, and key employees.	103,230	61,938	20,646	20,646
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).				
7	Other salaries and wages.	77,123	62,996	4,709	9,418
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).				
9	Other employee benefits.	11,922	8,259	1,676	1,987
10	Payroll taxes.	14,841	10,281	2,086	2,474
11	Fees for services (non-employees):				
a	Management.	254	0	254	0
b	Legal.				
c	Accounting.	21,280	0	21,280	0
d	Lobbying.				
e	Professional fundraising services. See Part IV, line 17.				
f	Investment management fees.				
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).				
12	Advertising and promotion.				
13	Office expenses.	66,744	31,905	8,088	26,751
14	Information technology.				
15	Royalties.				
16	Occupancy.				
17	Travel.				
18	Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19	Conferences, conventions, and meetings.	38,132	31,977	0	6,155
20	Interest.				
21	Payments to affiliates.	30	30	0	0
22	Depreciation, depletion, and amortization.	2,354	0	2,354	0
23	Insurance.	5,688	0	5,688	0
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	PROGRAM EXPENSES	61,083	61,083	0	0
b	PAYROLL PROCESSING FEES	1,565	1,084	220	261
c	CHARITABLE CONTRIBUTIONS	5,000	5,000	0	0
d	MEALS AND ENTERTAINMENT	6,096	5,105	0	991
e	All other expenses				
25	Total functional expenses. Add lines 1 through 24e.	498,433	362,749	67,001	68,683
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 to any question in this Part X

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			154,095	1	246,062
	2	Savings and temporary cash investments			232,636	2	259,225
	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				9	
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	9,390			
	b	Less accumulated depreciation	10b	4,759	4,776	10c	4,631
	11	Investments—publicly traded securities				11	
	12	Investments—other securities See Part IV, line 11			375,000	12	17,500
	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)			766,507	16	527,418
Liabilities	17	Accounts payable and accrued expenses			2,080	17	6,483
	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			2,080	26	6,483
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			513,086	27	269,594
	28	Temporarily restricted net assets				28	
	29	Permanently restricted net assets			251,341	29	251,341
	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			764,427	33	520,935
	34	Total liabilities and net assets/fund balances			766,507	34	527,418

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	254,941
2	Total expenses (must equal Part IX, column (A), line 25)	2	498,433
3	Revenue less expenses Subtract line 2 from line 1	3	-243,492
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	764,427
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	520,935

Part XII Financial Statements and Reporting

Check if Schedule O contains a response to any question 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	Yes	
2c	If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O		No
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.

OMB No 1545-0047

2012

Open to Public Inspection

Name of the organization
CHIARI & SYRINGOMYELIA FOUNDATION

Employer identification number
26-1316274

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 33¹/₃% 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 33¹/₃% 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									

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

Cat No 11285F

Schedule A (Form 990 or 990-EZ) 2012

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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
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						
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						0

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4						
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						0
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)						
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 501(c)(3) organization, check this box and stop here						▶

Section C. Computation of Public Support Percentage			
14 Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f))	14	0 %	
15 Public support percentage for 2011 Schedule A, Part II, line 14	15		
16a 33 1/3% support test—2012. 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—2011. 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—2012. 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—2011. 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 IIIPart III

Support 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	215,320	95,007	90,872	100,748	102,347	604,294
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	347,127	292,870	453,434	458,685	508,346	2,060,462
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	562,447	387,877	544,306	559,433	610,693	2,664,756
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)						2,664,756

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6	562,447	387,877	544,306	559,433	610,693	2,664,756
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.)						2,664,756
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 2012 (line 8, column (f) divided by line 13, column (f))	15	0 %
16 Public support percentage from 2011 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f))	17	0 %
18 Investment income percentage from 2011 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2012. 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—2011. 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.** Complete this part to 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

Explanation

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

OMB No 1545-0047

2012

Open to Public Inspection

Name of the organization
CHIARI & SYRINGOMYELIA FOUNDATION

Employer identification number
26-1316274

Part I

Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" to Form 990, Part IV, line 6.

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

Part II

Conservation Easements. Complete if the organization answered "Yes" to Form 990, Part IV, line 7.

1

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

☐ Preservation of land for public use (e g , recreation or education)

☐ Preservation of an historically important land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2

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

	Held at the End of the Year
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register

3

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

4

Number of states where property subject to conservation easement is located ▶ _____

5

Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?

☐ Yes ☐ No

6

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

7

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

8

Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?

☐ Yes ☐ No

9

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

Part III

Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

1a

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

b

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

(i) Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

(ii) Assets included in Form 990, Part X

▶ \$ _____

2

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

a

Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

b

Assets included in Form 990, Part X

▶ \$ _____

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Cat No 52283D

Schedule D (Form 990) 2012

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

3

Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply)

a

☐ Public exhibition

b

☐ Scholarly research

c

☐ Preservation for future generations

d

☐ Loan or exchange programs

e

☐ Other

4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII

5

During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes

☐ No

Part IV Escrow and Custodial Arrangements. Complete if the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a

Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIII and complete the following table

c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance

	Amount
1c	
1d	
1e	
1f	

2a

Did the organization include an amount on Form 990, Part X, line 21?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

☐

Part V Endowment Funds. Complete if the organization answered "Yes" to Form 990, Part IV, line 10.

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

2

Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as

a

Board designated or quasi-endowment

b

Permanent endowment

c

Temporarily restricted endowment

The percentages in lines 2a, 2b, and 2c should equal 100%

3a

Are there endowment funds not in the possession of the organization that are held and administered for the organization by

(i) unrelated organizations

3a(i)

Yes

No

(ii) related organizations

3a(ii)

Yes

No

b

If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

3b

Yes

No

4

Describe in Part XIII the intended uses of the organization's endowment funds

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

Description of property	(a) Cost or other basis (investment)	(b)Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment	9,390		4,759	4,631
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				4,631

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

1	Total revenue, gains, and other support per audited financial statements	1	612,441
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	357,500
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	357,500
3	Subtract line 2e from line 1	3	254,941
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)	5	254,941

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

1	Total expenses and losses per audited financial statements	1	498,433
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	498,433
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)	5	498,433

Part XIII Supplemental Information

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

Identifier	Return Reference	Explanation
------------	------------------	-------------

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.

Revenue			(a) Event #1	(b) Event #2	(c) Other events	(d) Total events	
			<u>NY CHARITY BALL</u>	<u>TASTE FOR A CURE</u>		(add col (a) through	
			(event type)	(event type)	(total number)	col (c))	
1	Gross receipts	. . .					
2	Less Contributions	. .					
3	Gross income (line 1 minus line 2)	. . .					
Direct Expenses	4	Cash prizes	. . .				
	5	Noncash prizes	. .				
	6	Rent/facility costs	. .				
	7	Food and beverages	.				
	8	Entertainment	. . .				
	9	Other direct expenses	.				
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶					()
	11	Net income summary Combine line 3, column (d), and line 10 ▶					

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.

Revenue		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
1	Gross revenue				
Direct Expenses	2 Cash prizes				
	3 Non-cash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
	6 Volunteer labor	☐ Yes _____ ☒ No	☐ Yes _____ ☒ No	☐ Yes _____ ☒ No	
7	Direct expense summary Add lines 2 through 5 in column (d) ➤				
8	Net gaming income summary Combine lines 1 and 7 in 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  DOROTHY POPPE

Address  29 CREST LOOP
STATEN ISLAND, NY 10312

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. Complete this part to 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).

Identifier	Return Reference	Explanation
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Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

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

OMB No 1545-0047

2012

Open to Public
Inspection

Name of the organization
CHIARI & SYRINGOMYELIA FOUNDATION

Employer identification number
26-1316274

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

2

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

▶

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

Part IV Supplemental Information.		
Complete this part to provide the information required in Part I, line 2, Part III, column (b), and any other additional information		
Identifier	Return Reference	Explanation

SCHEDULE M
(Form 990)

Noncash Contributions

OMB No 1545-0047

2012

Open to Public Inspection

►Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
► Attach to Form 990.

Name of the organization
CHIARI & SYRINGOMYELIA FOUNDATION

Employer identification number
26-1316274

Part I

Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art—Works of art				
2 Art—Historical treasures				
3 Art—Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities—Publicly traded				
10 Securities—Closely held stock				
11 Securities—Partnership, LLC, or trust interests				
12 Securities—Miscellaneous				
13 Qualified conservation contribution—Historic structures				
14 Qualified conservation contribution—Other				
15 Real estate—Residential				
16 Real estate—Commercial				
17 Real estate—Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ► ()				
26 Other ►()				
27 Other ►()				
28 Other ► ()				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement29

30a During the year, did the organization receive by contribution any property reported in Part I, lines 1-28 that it must hold for at least three years from the date of the initial contribution, and which is not required to be used for exempt purposes for the entire holding period?

31 If "Yes," describe the arrangement in Part II

32a Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?

33a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

33b If "Yes," describe in Part II

33 If the organization did not report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II

Yes

No

No

Yes

No

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

Cat No 51227J

Schedule M (Form 990) (2012)

Part II

Supplemental Information. Complete this part to provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

Identifier	Return Reference	Explanation
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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.**

OMB No 1545-0047

2012**Open to Public
Inspection**Name of the organization
CHIARI & SYRINGOMYELIA FOUNDATION**Employer identification number**

26-1316274

Identifier	Return Reference	Explanation
Pt VI, Line 11b		EXECUTIVE DIRECTOR AND CHARIMAN OF BOARD REVIEW RETURN PRIOR TO FILING FINANCIAL STATEMENTS REVIEWED ON MONTHLY BASIS BY BOARD MEMBERS
Pt VI, Line 15a		COMPENSATION FOR EXECUTIVE DIRECTOR IS REVIEWED AND APPROVED BY MEMBERS OF THE BOARD
Pt VI, Line 15b		COMPENSATION FOR OFFICERS AND KEY EMPLOYEES IS REVIEWED AND APPROVED BY BOARD
Pt VI, Line 12c		BOARD MEMBERS SIGN A DOCUMENT STATING THAT THEY RECIEVED THE POLICY, READ AND UNDERSTAND IT, AND AGREE TO COMPLY
Pt VI, Line 19		ITEMS ARE AVAILABLE VIA ENTITY WEBSITE AND GUIDESTAR WE CURRENTLY HAVE GUIDESTAR SEAL OF APPROVAL
Pt XII, Line 1		CHANGED METHOD OF ACCOUNTING FROM CASH TO ACCRUAL IN 2011
Form 990EZ, Part II, Line 24		DONATION RECEIVABLE
Form 990EZ, Part II, Line 26		ACCRUED PAY ROLL TAXES

Form **4562**

Department of the Treasury
Internal Revenue Service (99)

Depreciation and Amortization
(Including Information on Listed Property)

▶ See separate instructions. ▶ Attach to your tax return.

OMB No 1545-0172

2012

Attachment
Sequence No **179**

Name(s) shown on return
CHIARI & SYRINGOMYELIA FOUNDATION

Business or activity to which this form relates
Form 990 / Form 990EZ

Identifying number

26-1316274

Part I Election To Expense Certain Property Under Section 179

Note: If you have any listed property, complete Part V before you complete Part I.

1	Maximum amount (see instructions)	1	
2	Total cost of section 179 property placed in service (see instructions)	2	
3	Threshold cost of section 179 property before reduction in limitation (see instructions)	3	\$ 2,000,000
4	Reduction in limitation Subtract line 3 from line 2 If zero or less, enter -0-	4	
5	Dollar limitation for tax year Subtract line 4 from line 1 If zero or less, enter -0- If married filing separately, see instructions	5	

6	(a) Description of property	(b) Cost (business use only)	(c) Elected cost	
6				
7	Listed property Enter the amount from line 29	7		
8	Total elected cost of section 179 property Add amounts in column (c), lines 6 and 7	8		
9	Tentative deduction Enter the smaller of line 5 or line 8	9		
10	Carryover of disallowed deduction from line 13 of your 2011 Form 4562	10		
11	Business income limitation Enter the smaller of business income (not less than zero) or line 5 (see instructions)	11		
12	Section 179 expense deduction Add lines 9 and 10, but do not enter more than line 11	12		
13	Carryover of disallowed deduction to 2013 Add lines 9 and 10, less line 12	13		

Note: Do not use Part II or Part III below for listed property. Instead, use Part V.

Part II Special Depreciation Allowance and Other Depreciation (Do not include listed property) (See instructions)

14	Special depreciation allowance for qualified property (other than listed property) placed in service during the tax year (see instructions)	14	
15	Property subject to section 168(f)(1) election	15	
16	Other depreciation (including ACRS)	16	

Part III MACRS Depreciation (Do not include listed property.) (See instructions.)

Section A

17	MACRS deductions for assets placed in service in tax years beginning before 2012	17	1,912
18	If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here		

Section B—Assets Placed in Service During 2012 Tax Year Using the General Depreciation System

(a) Classification of property	(b) Month and year placed in service	(c) Basis for depreciation (business/investment use only—see instructions)	(d) Recovery period	(e) Convention	(f) Method	(g) Depreciation deduction
19a 3-year property						
b 5-year property		2,209	5	HY	200 DB	442
c 7-year property						
d 10-year property						
e 15-year property						
f 20-year property						
g 25-year property			25 yrs		S/L	
h Residential rental property			27 5 yrs	MM	S/L	
			27 5 yrs	MM	S/L	
i Nonresidential real property			39 yrs	MM	S/L	
				MM	S/L	

Section C—Assets Placed in Service During 2012 Tax Year Using the Alternative Depreciation System

20a Class life					S/L	
b 12-year			12 yrs		S/L	
c 40-year			40 yrs	MM	S/L	

Part IV Summary (see instructions)

21	Listed property Enter amount from line 28	21	
22	Total. Add amounts from line 12, lines 14 through 17, lines 19 and 20 in column (g), and line 21 Enter here and on the appropriate lines of your return Partnerships and S corporations—see instructions	22	2,354
23	For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs	23	

Part V

Listed Property (Include automobiles, certain other vehicles, certain computers, and property used for entertainment, recreation, or amusement.)
Note: For any vehicle for which you are using the standard mileage rate or deducting lease expense, complete **only** 24a, 24b, columns (a) through (c) of Section A, all of Section B, and Section C if applicable.

Section A—Depreciation and Other Information (Caution: See the instructions for limits for passenger automobiles.)

24a Do you have evidence to support the business/investment use claimed? ☐ Yes ☐ No						24b If "Yes," is the evidence written? ☐ Yes ☐ No			
(a) Type of property (list vehicles first)	(b) Date placed in service	(c) Business/ investment use percentage	(d) Cost or other basis	(e) Basis for depreciation (business/investment use only)	(f) Recovery period	(g) Method/ Convention	(h) Depreciation/ deduction	(i) Elected section 179 cost	
25Special depreciation allowance for qualified listed property placed in service during the tax year and used more than 50% in a qualified business use (see instructions)						25			
26 Property used more than 50% in a qualified business use									
		%							
		%							
		%							
27 Property used 50% or less in a qualified business use									
		%				S/L -			
		%				S/L -			
		%				S/L -			
28 Add amounts in column (h), lines 25 through 27 Enter here and on line 21, page 1						28			
29 Add amounts in column (i), line 26 Enter here and on line 7, page 1							29		

Section B—Information on Use of Vehicles

Complete this section for vehicles used by a sole proprietor, partner, or other "more than 5% owner," or related person
If you provided vehicles to your employees, first answer the questions in Section C to see if you meet an exception to completing this section for those vehicles

30 Total business/investment miles driven during the year (do not include commuting miles) . . .	(a) Vehicle 1		(b) Vehicle 2		(c) Vehicle 3		(d) Vehicle 4		(e) Vehicle 5		(f) Vehicle 6	
31 Total commuting miles driven during the year . . .												
32 Total other personal(noncommuting) miles driven . . .												
33 Total miles driven during the year Add lines 30 through 32												
34 Was the vehicle available for personal use during off-duty hours?	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
35 Was the vehicle used primarily by a more than 5% owner or related person?												
36 Is another vehicle available for personal use? . . .												

Section C—Questions for Employers Who Provide Vehicles for Use by Their Employees

Answer these questions to determine if you meet an exception to completing Section B for vehicles used by employees who **are not** more than 5% owners or related persons (see instructions)

37 Do you maintain a written policy statement that prohibits all personal use of vehicles, including commuting, by your employees?	Yes	No
38 Do you maintain a written policy statement that prohibits personal use of vehicles, except commuting, by your employees? See the instructions for vehicles used by corporate officers, directors, or 1% or more owners		
39 Do you treat all use of vehicles by employees as personal use?		
40 Do you provide more than five vehicles to your employees, obtain information from your employees about the use of vehicles, and retain the information received?		
41 Do you meet the requirements concerning qualified automobile demonstration use? (See instructions)		
Note: If your answer to 37, 38, 39, 40, or 41 is "Yes," do not complete Section B for the covered vehicles		

Part VI Amortization

(a) Description of costs	(b) Date amortization begins	(c) Amortizable amount	(d) Code section	(e) Amortization period or percentage	(f) Amortization for this year
42 Amortization of costs that begins during your 2012 tax year (see instructions)					
43 Amortization of costs that began before your 2012 tax year				43	
44 Total. Add amounts in column (f) See the instructions for where to report				44	