

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

2013

Department of the Treasury
Internal Revenue Service

Do not enter Social Security numbers on this form as it may be made public.

Information about Form 990 and its instructions is at www.irs.gov/form990.

Open to Public Inspection

A For the 2013 calendar year, or tax year beginning and ending


B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization HYDROCEPHALUS ASSOCIATION Doing Business As		D Employer identification number 94-3000301
	Number and street (or P.O. box if mail is not delivered to street address) Room/suite 4340 EAST WEST HIGHWAY 905		E Telephone number (301)202-3811
	City or town, state or province, country, and ZIP or foreign postal code BETHESDA, MD 20814		G Gross receipts \$ 3,720,121.
	F Name and address of principal officer: DAWN MANCUSO SAME AS C ABOVE		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) H(c) Group exemption number
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527			
J Website: WWW.HYDROASSOC.ORG			
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other			L Year of formation: 1986
M State of legal domicile: CA			

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: THE HYDROCEPHALUS ASSOCIATION COLLABORATES WITH PATIENTS, CAREGIVERS, RESEARCHERS AND INDUSTRY TO		
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	15
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	15
	5 Total number of individuals employed in calendar year 2013 (Part V, line 2a)	5	13
	6 Total number of volunteers (estimate if necessary)	6	1200
	7 a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, line 34	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9 Program service revenue (Part VIII, line 2g)	2,247,530.	3,595,186.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	76,921.	0.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	10,774.	3,066.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	-121,354.	-136,816.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	2,213,871.	3,461,436.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	111,122.	861,623.
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	0.	0.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	820,867.	872,934.
	b Total fundraising expenses (Part IX, column (D), line 25)	31,200.	0.
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	875,313.	682,981.
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	1,838,502.	2,417,538.
Net Assets or Fund Balances	19 Revenue less expenses. Subtract line 18 from line 12	375,369.	1,043,898.
	20 Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	21 Total liabilities (Part X, line 26)	1,652,061.	2,771,059.
	22 Net assets or fund balances. Subtract line 21 from line 20	194,607.	274,841.
		1,457,454.	2,496,218.

Part II Signature Block

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

Sign Here	Signature of officer DAWN MANCUSO, CHIEF EXECUTIVE OFFICER		Date	
	Type or print name and title			
Paid Preparer Use Only	Print/Type preparer's name HYDEH GHAFFARI	Preparer's signature 	Date 11/11/14	Check if self-employed <input checked="" type="checkbox"/> PTIN P01228587
	Firm's name DZH PHILLIPS LLP	Firm's address 1330 BROADWAY, SUITE 630 OAKLAND, CA 94612		Firm's EIN 26-4677183
			Phone no. 510-834-6542	

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: THE MISSION OF THE HYDROCEPHALUS ASSOCIATION IS TO PROMOTE A CURE FOR HYDROCEPHALUS AND IMPROVE THE LIVES OF THOSE AFFECTED BY THE CONDITION.

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 [X] No

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

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 \$ 1,120,776. including grants of \$) (Revenue \$)

RESEARCH: THIS YEAR (2013) MARKED THE END OF PHASE ONE OF OUR REASON FOR HOPE RESEARCH FUNDING CAMPAIGN, WHICH STARTED IN 2009 TO FUND THE HYDROCEPHALUS ASSOCIATION'S (HA) RESEARCH INITIATIVE. WE ARE PROUD TO REPORT THAT AS A COMMUNITY WE SURPASSED OUR \$3 MILLION FUNDING GOAL, RAISING A TOTAL OF \$3,065,046 FOR HYDROCEPHALUS RESEARCH. OVER THE PAST FIVE YEARS, HA HAS FUNDED A TOTAL OF \$2.7 MILLION IN BOTH BASIC AND CLINICAL HYDROCEPHALUS RESEARCH. THESE RESEARCH PROJECTS ARE FOCUSED ON UNDERSTANDING THE CAUSES OF HYDROCEPHALUS AND DEVELOPING BETTER TREATMENTS IN ORDER TO, ULTIMATELY, FIND A CURE. IN 2013, WE PARTNERED WITH THE RUDI SCHULTE RESEARCH INSTITUTE (RSRI) TO FUND A NEW RESEARCH VENTURE. RSRI CHOSE MARK WAGSHUL, PHD, FOR HIS

4b (Code:) (Expenses \$ 282,200. including grants of \$) (Revenue \$)

PUBLIC SUPPORT AND EDUCATION: THE HYDROCEPHALUS ASSOCIATION IS COMMITTED TO PROVIDING INNOVATIVE PROGRAMS TO MEET THE DIVERSE NEEDS OF PATIENTS AND THEIR CAREGIVERS. OUR SERVICES ENSURE THAT PATIENTS BATTLING HYDROCEPHALUS HAVE A PLACE TO TURN TO FOR RESOURCES AND PEER-TO-PEER SUPPORT. IN 2013, WE PUBLISHED SEVERAL NEW EDUCATIONAL MATERIALS, PROVIDED THOUSANDS OF HOURS OF ONE-ON-ONE SUPPORT THROUGH PHONE, MAIL, EMAIL, AND SOCIAL MEDIA TO HELP PATIENTS AND THEIR FAMILIES, AND EXPANDED OUR REACH BY RESTRUCTURING THE HYDROCEPHALUS COMMUNITY NETWORKS. WE LAUNCHED A NEW WEBINAR SERIES, DESIGNED TO DELIVER VITAL INFORMATION TO OUR COMMUNITY WHERE THEY LIVE AND WORK. THESE INTERACTIVE, FREE SESSIONS FEATURE PRESENTATIONS FROM MEDICAL PROFESSIONALS, RESEARCHERS,

4c (Code:) (Expenses \$ 41,721. including grants of \$) (Revenue \$)

ADVOCACY: IN 2013, THE ASSOCIATION DEVELOPED A STEERING COMMITTEE TO OVERSEE ITS ADVOCACY EFFORTS; EXPANDED IT WORK WITH A NUMBER OF NATIONAL HEALTH ADVOCACY GROUPS AND COALITIONS, AND EDUCATED MEMBERS OF CONGRESS AND OTHER PUBLIC POLICY MAKERS ABOUT THE NEED FOR MORE FUNDING FOR HYDROCEPHALUS RESEARCH. ADVOCACY STEERING COMMITTEE: TO HELP DEVELOP AND DRIVE THE ASSOCIATION'S ADVOCACY STRATEGY, AN ADVOCACY STEERING COMMITTEE WAS ESTABLISHED IN 2013. THE COMMITTEE DEVELOPS THE WORK PLAN AND TACTICS EMPLOYED EACH YEAR TO ULTIMATELY ACHIEVE OUR PRIMARY ADVOCACY GOAL -- TO ENSURE THE FEDERAL GOVERNMENT INVESTS ADEQUATE FUNDS TO SUPPORT PATIENTS AND THEIR CAREGIVERS. SPECIFICALLY, THE COMMITTEE WILL ENSURE

4d Other program services (Describe in Schedule O.) (Expenses \$ 24,541. including grants of \$) (Revenue \$)

4e Total program service expenses 1,469,238.

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)? <i>If "Yes," complete Schedule A</i>	X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ?	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
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? <i>If "Yes," complete Schedule C, Part II</i>	X	
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? <i>If "Yes," complete Schedule C, Part III</i>		X
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? <i>If "Yes," complete Schedule D, Part I</i>		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
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? <i>If "Yes," complete Schedule D, Part IV</i>		X
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>	X	
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? <i>If "Yes," complete Schedule D, Part VI</i>	X	
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? <i>If "Yes," complete Schedule D, Part VII</i>		X
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? <i>If "Yes," complete Schedule D, Part VIII</i>		X
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? <i>If "Yes," complete Schedule D, Part IX</i>		X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>	X	
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)? <i>If "Yes," complete Schedule D, Part X</i>		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
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? <i>If "Yes," complete Schedule F, Parts I and IV</i>		X
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? <i>If "Yes," complete Schedule F, Parts II and IV</i>		X
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? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
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? <i>If "Yes," complete Schedule G, Part I</i>		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
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)

	Yes	No
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>	X	
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>	X	
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>	X	
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>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
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?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
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>		X
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>		X
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>		X
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>		X
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>		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
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>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	X	
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>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
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>		X
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>		X
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>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
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>		
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>		X
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>		X
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	X	

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

Table with columns for question number, question text, and Yes/No columns. Includes questions 1a through 14b regarding Form 1096, Form W-2G, backup withholding, Form W-3, unrelated business gross income, foreign accounts, prohibited tax shelter transactions, annual gross receipts, and sponsoring organizations.

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 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 [X]

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year (15); 1b Enter the number of voting members included in line 1a, above, who are independent (15); 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? (X); 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? (X); 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? (X); 5 Did the organization become aware during the year of a significant diversion of the organization's assets? (X); 6 Did the organization have members or stockholders? (X); 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? (X); 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? (X); 8a The governing body? (X); 8b Each committee with authority to act on behalf of the governing body? (X); 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 (X).

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? (X); 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?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? (X); 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 (X); 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? (X); 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done (X); 13 Did the organization have a written whistleblower policy? (X); 14 Did the organization have a written document retention and destruction policy? (X); 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 (X); 15b Other officers or key employees of the organization (X); 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? (X); 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?

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed AL, AK, AR, CA, CT, FL, GA, IL, KS, KY, ME, MD
18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. [] Own website [] Another's website [X] 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: DAWN MANCUSO - (301)201-3811 4340 EAST WEST HIGHWAY, NO. 905, BETHESDA, MD 20814

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

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

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

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See 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, and 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 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) BARRETT O'CONNOR CHAIR	12.00	X		X				0.	0.	0.
(2) CRAIG BROWN SENIOR VICE CHAIRMAN	2.00	X		X				0.	0.	0.
(3) DAVID BROWDY VICE CHAIR	2.00	X		X				0.	0.	0.
(4) ASEEM CHANDRA VICE CHAIR	2.00	X		X				0.	0.	0.
(5) RICK SMITH TREASURER	2.00	X		X				0.	0.	0.
(6) PAUL GROSS SECRETARY/PAST CHAIR	2.00	X		X				0.	0.	0.
(7) RALPH KISTLER DIRECTOR	2.00	X						0.	0.	0.
(8) MARVIN SUSSMAN DIRECTOR	2.00	X						0.	0.	0.
(9) RUSSELL FUDGE DIRECTOR	2.00	X						0.	0.	0.
(10) DEBBY BUFFA DIRECTOR	2.00	X						0.	0.	0.
(11) MIKE SCHWAB DIRECTOR	2.00	X						0.	0.	0.
(12) MARION WALKER DIRECTOR	2.00	X						0.	0.	0.
(13) JOHN KESTLE DIRECTOR	2.00	X						0.	0.	0.
(14) JOHN LAWRENCE DIRECTOR	2.00	X						0.	0.	0.
(15) SHANNON O'CONNOR DIRECTOR	2.00	X						0.	0.	0.
(16) DAWN MANCUSO CEO	54.00			X				180,250.	0.	12,193.

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	1 a	Federated campaigns					
	b	Membership dues					
	c	Fundraising events	1,190,006.				
	d	Related organizations					
	e	Government grants (contributions)					
	f	All other contributions, gifts, grants, and similar amounts not included above	2,405,180.				
	g	Noncash contributions included in lines 1a-1f: \$	100,913.				
	h	Total. Add lines 1a-1f	3,595,186.				
	Program Service Revenue	2 a					
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)		5,502.		5,502.	
	4	Income from investment of tax-exempt bond proceeds					
	5	Royalties					
	6 a		(i) Real				
			(ii) Personal				
		b	Gross rents				
		c	Less: rental expenses				
	d	Net rental income or (loss)					
	7 a		(i) Securities				
			(ii) Other				
		b	Gross amount from sales of assets other than inventory	98,477.			
		c	Less: cost or other basis and sales expenses	100,913.			
	d	Net gain or (loss)	-2,436.	-2,436.			
	8 a		Gross income from fundraising events (not including \$ 1,190,006. of contributions reported on line 1c). See Part IV, line 18				
		b	Less: direct expenses				
		c	Net income or (loss) from fundraising events		-157,772.		-157,772.
	9 a		Gross income from gaming activities. See Part IV, line 19				
b		Less: direct expenses					
c		Net income or (loss) from gaming activities					
10 a		Gross sales of inventory, less returns and allowances					
	b	Less: cost of goods sold					
	c	Net income or (loss) from sales of inventory		5,605.	5,605.		
Miscellaneous Revenue							
11 a		OTHER INCOME	900099	15,351.		15,351.	
	b						
	c						
	d	All other revenue					
	e	Total. Add lines 11a-11d		15,351.			
12	Total revenue. See instructions.		3,461,436.	3,169.	0.	-136,919.	

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	845,623.	845,623.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22	16,000.	16,000.		
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	192,443.	53,443.	104,769.	34,231.
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	547,623.	243,876.	63,871.	239,876.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	7,766.	3,678.	347.	3,741.
9 Other employee benefits	71,596.	35,608.	11,446.	24,542.
10 Payroll taxes	53,506.	21,995.	11,941.	19,570.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	43,972.		43,972.	
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 Sch O.)	57,001.	33,444.	5,881.	17,676.
12 Advertising and promotion	2,641.	579.	2,062.	
13 Office expenses	199,139.	51,694.	18,893.	128,552.
14 Information technology	44,335.	10,153.	16,576.	17,606.
15 Royalties				
16 Occupancy	101,690.	64,140.	14,070.	23,480.
17 Travel	120,502.	20,710.	39,642.	60,150.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	3,697.	3,525.		172.
20 Interest	2,081.	1,312.	283.	486.
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	16,320.	10,294.	2,258.	3,768.
23 Insurance	5,977.	2,830.	2,111.	1,036.
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 FOOD, MEALS & CATERING	46,040.	35,217.	5,858.	4,965.
b SITE EXPENSES	15,646.	8,227.	623.	6,796.
c TAXES & OTHER FEES	7,361.	2,031.	1,966.	3,364.
d DUES & SUBSCRIPTIONS	6,809.	3,239.	2,734.	836.
e All other expenses SEE SCH O	9,770.	1,620.	6,244.	1,906.
25 Total functional expenses. Add lines 1 through 24e	2,417,538.	1,469,238.	355,547.	592,753.
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) Beginning of year		(B) End of year
Assets	1 Cash - non-interest-bearing	1,132,500.	1	1,952,896.
	2 Savings and temporary cash investments		2	
	3 Pledges and grants receivable, net	76,500.	3	403,717.
	4 Accounts receivable, net	38,834.	4	392.
	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 instr). Complete Part II of Sch L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use	16,525.	8	9,151.
	9 Prepaid expenses and deferred charges	12,760.	9	50,769.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 81,752.		
	b Less: accumulated depreciation	10b 42,224.		
	11 Investments - publicly traded securities	52,617.	10c	39,528.
	12 Investments - other securities. See Part IV, line 11	312,216.	11	303,498.
	13 Investments - program-related. See Part IV, line 11		12	
	14 Intangible assets		13	
	15 Other assets. See Part IV, line 11	10,109.	14	
16 Total assets. Add lines 1 through 15 (must equal line 34)	1,652,061.	15	11,108.	
		16	2,771,059.	
Liabilities	17 Accounts payable and accrued expenses	99,677.	17	264,412.
	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	94,930.	25	10,429.
	26 Total liabilities. Add lines 17 through 25	194,607.	26	274,841.
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	900,005.	27	1,840,302.
	28 Temporarily restricted net assets	476,331.	28	574,798.
	29 Permanently restricted net assets	81,118.	29	81,118.
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> 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	1,457,454.	33	2,496,218.	
34 Total liabilities and net assets/fund balances	1,652,061.	34	2,771,059.	

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	3,461,436.
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,417,538.
3	Revenue less expenses. Subtract line 2 from line 1	3	1,043,898.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,457,454.
5	Net unrealized gains (losses) on investments	5	-5,134.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	2,496,218.

Part XII Financial Statements and Reporting

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

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

Form 990 (2013)

SCHEDULE A
(Form 990 or 990-EZ)

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.

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

Name of the organization HYDROCEPHALUS ASSOCIATION	Employer identification number 94-3000301
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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?

	Yes	No
(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).

(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.")	1,701,538.	1,786,923.	1,689,904.	2,247,530.	3,595,186.	11,021,081.
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	1,701,538.	1,786,923.	1,689,904.	2,247,530.	3,595,186.	11,021,081.
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)						1,629,195.
6 Public support. Subtract line 5 from line 4.						9,391,886.

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	1,701,538.	1,786,923.	1,689,904.	2,247,530.	3,595,186.	11,021,081.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	7,012.	17,679.	11,892.	13,640.	5,502.	55,725.
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.)	2,773.	4,780.	3,225.	5,867.	15,351.	31,996.
11 Total support. Add lines 7 through 10						11,108,802.
12 Gross receipts from related activities, etc. (see instructions)					12	198,307.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f))	14	84.54 %
15 Public support percentage from 2012 Schedule A, Part II, line 14	15	82.18 %
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 <input checked="" type="checkbox"/>		
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 <input type="checkbox"/>		
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 <input type="checkbox"/>		
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 <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions <input type="checkbox"/>		

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

(Complete only if you checked the box on line 9 of Part I 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 section 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	%
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	%
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 ►

SCHEDULE C
(Form 990 or 990-EZ)

Political Campaign and Lobbying Activities

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

For Organizations Exempt From Income Tax Under section 501(c) and section 527
▶ **Complete if the organization is described below.** ▶ **Attach to Form 990 or Form 990-EZ.**
▶ **See separate instructions.** ▶ **Information about Schedule C (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.**

If the organization answered "Yes," to Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes," to Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

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

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

Name of organization HYDROCEPHALUS ASSOCIATION	Employer identification number 94-3000301
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Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

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

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

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ \$ _____
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$ _____
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? Yes No
- 4a Was a correction made? Yes No
- b If "Yes," describe in Part IV.

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

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ \$ _____
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ \$ _____
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b ▶ \$ _____
- 4 Did the filing organization file **Form 1120-POL** for this year? Yes No
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0-.	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

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

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

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

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes," response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?	X		
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	X		
c Media advertisements?		X	
d Mailings to members, legislators, or the public?	X		129.
e Publications, or published or broadcast statements?	X		397.
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?	X		78.
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?		X	
j Total. Add lines 1c through 1i			604.
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

	Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?	3	

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No," OR (b) Part III-A, line 3, is answered "Yes."

1 Dues, assessments and similar amounts from members	1
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).	
a Current year	2a
b Carryover from last year	2b
c Total	2c
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?	4
5 Taxable amount of lobbying and political expenditures (see instructions)	5

Part IV Supplemental Information

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

PART II-B, LINE 1, LOBBYING ACTIVITIES:

EXPLANATION: AS PART OF OUR PROGRAM TO EDUCATE CONGRESS AND OTHERS

ABOUT THE NEEDS OF HYDROCEPHALUS PATIENTS AND THEIR FAMILIES, AND TO

ADVOCATE FOR MORE FUNDING FOR HYDROCEPHALUS RESEARCH, THE HYDROCEPHALUS

ASSOCIATION PARTICIPATED IN A NUMBER OF COALITIONS (INCLUDING THE

NATIONAL HEALTH COUNCIL, THE AMERICAN BRAIN COALITION, AND

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

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

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

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization

HYDROCEPHALUS ASSOCIATION

Employer identification number

94-3000301

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?		<input type="checkbox"/> Yes <input type="checkbox"/> 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?		<input type="checkbox"/> Yes <input type="checkbox"/> 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 Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register	2d

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

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

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? Yes No

6 Staff and volunteer hours devoted to monitoring, inspecting, 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 ▶ \$

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:

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

2a Did the organization include an amount on Form 990, Part X, line 21? 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	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	81,118.	80,818.	80,718.	80,218.	80,218.
b Contributions		300.	100.	500.	
c Net investment earnings, gains, and losses	105.	4,731.	1,386.	3,895.	1,071.
d Grants or scholarships	105.	4,731.	1,386.	3,895.	1,071.
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	81,118.	81,118.	80,818.	80,718.	80,218.

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 100.00 %
- 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:

	Yes	No
(i) unrelated organizations		X
(ii) related organizations		X
b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?	3b	

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

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		71,166.	31,638.	39,528.
e Other		10,586.	10,586.	0.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				39,528.

Part VII Investments - Other Securities.

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

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ▶		

Part VIII Investments - Program Related.

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

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

Part IX Other Assets.

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

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

Part X Other Liabilities.

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) LEASE PAYABLE	10,429.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

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

Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	3,456,304.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains on investments	2a	-5,134.	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d	2.	
e	Add lines 2a through 2d	2e	-5,132.	
3	Subtract line 2e from line 1	3	3,461,436.	
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c	0.	
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	3,461,436.	

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

Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	2,417,538.
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	0.	
3	Subtract line 2e from line 1	3	2,417,538.	
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c	0.	
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5	2,417,538.	

Part XIII Supplemental Information.

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

PART V, LINE 4:

EXPLANATION: THE ORGANIZATION USES ENDOWMENT FUNDS FOR EDUCATIONAL SCHOLARSHIPS TO YOUNG ADULTS WITH HYDROCEPHALUS.

PART XI, LINE 2D - OTHER ADJUSTMENTS:

SMALL DIFFERENT ADJUSTMENT

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 (add col. (a) through col. (c))	
		WALK-A-THON (LOS ANGELES) (event type)	WALK-A-THON (CHICAGO) (event type)	31 (total number)		
Revenue	1	Gross receipts	130,434.	90,998.	968,574.	1,190,006.
	2	Less: Contributions	130,434.	90,998.	968,574.	1,190,006.
	3	Gross income (line 1 minus line 2)				
Direct Expenses	4	Cash prizes				
	5	Noncash prizes	3,671.	5,059.	49,030.	57,760.
	6	Rent/facility costs	3,989.	900.	11,308.	16,197.
	7	Food and beverages	271.	680.	13,130.	14,081.
	8	Entertainment	2,795.	400.	12,124.	15,319.
	9	Other direct expenses	1,453.	7,302.	45,660.	54,415.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				157,772.
11	Net income summary. Subtract line 10 from line 3, column (d)				-157,772.	

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			
Direct Expenses	2	Cash prizes			
	3	Noncash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> 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: _____

- 11 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 to be 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).

**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.

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

OMB No. 1545-0047

2013

Open to Public
Inspection

Name of the organization

HYDROCEPHALUS ASSOCIATION

Employer identification number
94-3000301

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?
 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Yes No

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.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF UTAH 175 NORTH MEDICAL DRIVE SALT LAKE CITY, UT 84132	87-6000525	501(C)(3)	160,000.	0.			DR. MCALLISTER'S STUDY INVESTIGATES THE ABNORMAL BLOCKAGE OF CEREBROSPINAL FLUID FLOW. THE STUDY TO FUND HYDROCEPHALUS RESEARCH CONDUCTED AT THE HYDROCEPHALUS CLINICAL RESEARCH NETWORK.
PRIMARY CHILDREN'S MEDICAL CENTER FOUNDATION - 100 N. MARIO CAPPECHI DRIVE - SALT LAKE CITY, UT 84113	87-0453633	501(C)(3)	500,063.	0.			FUNDING FOR STUDYING THE ROLE OF NEURAL PROGENITOR CELLS IN THE DEVELOPMENT OF NEONATAL
CHILDREN'S HOSPITAL MEDICAL CENTER/OHIO - 3333 BURNEY AVENUE, ML 4900 - CINCINNATI, OH 45229	31-0537130	501(C)(3)	133,000.	0.			TO FUND HYDROCEPHALUS RESEARCH CONDUCTED AT THE LOCAL HYDROCEPHALUS CLINICAL RESEARCH NETWORK
UNIVERSITY OF ALABAMA BIRMINGHAM 1720 2ND AVENUE SOUTH BIRMINGHAM, AL 35294	63-6005396	501(C)(3)	50,000.	0.			

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

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

SEE PART IV FOR COLUMN (H) DESCRIPTIONS

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
SCHOLARSHIPS	16	16,000.	0.		

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

PART I, LINE 2:

EXPLANATION: GRANTEES PROVIDE PROGRESS REPORTS AND THESE ARE MONITORED AGAINST OUR RESEARCH OBJECTIVES. THESE ARE THEN REVIEWED BY SENIOR STAFF AND MEMBERS OF THE RESEARCH COMMITTEE.

PART II, LINE 1, COLUMN (H):

NAME OF ORGANIZATION OR GOVERNMENT: UNIVERSITY OF UTAH

(H) PURPOSE OF GRANT OR ASSISTANCE: DR. MCALLISTER'S STUDY INVESTIGATES

THE ABNORMAL BLOCKAGE OF CEREBROSPINAL FLUID FLOW. THE STUDY USES ANIMAL

Part IV Supplemental Information

MODELS AND PATIENT CSF TO INCREASE OUR UNDERSTANDING OF THE DAMAGE THAT OCCURS IN THE HYDROCEPHALIC BRAIN. USING THIS INFORMATION CAN HELP ADVANCE THE DEVELOPMENT OF NOVEL TRANSPLANTATION THERAPIES.

NAME OF ORGANIZATION OR GOVERNMENT:

CHILDREN'S HOSPITAL MEDICAL CENTER/OHIO

(H) PURPOSE OF GRANT OR ASSISTANCE: FUNDING FOR STUDYING THE ROLE OF NEURAL PROGENITOR CELLS IN THE DEVELOPMENT OF NEONATAL HYDROCEPHALUS.

NAME OF ORGANIZATION OR GOVERNMENT: UNIVERSITY OF ALABAMA BIRMINGHAM

(H) PURPOSE OF GRANT OR ASSISTANCE: TO FUND HYDROCEPHALUS RESEARCH CONDUCTED AT THE LOCAL HYDROCEPHALUS CLINICAL RESEARCH NETWORK SITE.

**SCHEDULE J
(Form 990)**

Compensation Information

OMB No. 1545-0047

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

2013

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.

▶ Attach to Form 990. ▶ See separate instructions.

Open to Public Inspection

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

Department of the Treasury
Internal Revenue Service

Name of the organization

HYDROCEPHALUS ASSOCIATION

Employer identification number

94-3000301

Part I Questions Regarding Compensation

		Yes	No								
<p>1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed in Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.</p> <table border="0"> <tr> <td><input type="checkbox"/> First-class or charter travel</td> <td><input type="checkbox"/> Housing allowance or residence for personal use</td> </tr> <tr> <td><input type="checkbox"/> Travel for companions</td> <td><input type="checkbox"/> Payments for business use of personal residence</td> </tr> <tr> <td><input type="checkbox"/> Tax indemnification and gross-up payments</td> <td><input type="checkbox"/> Health or social club dues or initiation fees</td> </tr> <tr> <td><input type="checkbox"/> Discretionary spending account</td> <td><input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef)</td> </tr> </table>				<input type="checkbox"/> First-class or charter travel	<input type="checkbox"/> Housing allowance or residence for personal use	<input type="checkbox"/> Travel for companions	<input type="checkbox"/> Payments for business use of personal residence	<input type="checkbox"/> Tax indemnification and gross-up payments	<input type="checkbox"/> Health or social club dues or initiation fees	<input type="checkbox"/> Discretionary spending account	<input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef)
<input type="checkbox"/> First-class or charter travel	<input type="checkbox"/> Housing allowance or residence for personal use										
<input type="checkbox"/> Travel for companions	<input type="checkbox"/> Payments for business use of personal residence										
<input type="checkbox"/> Tax indemnification and gross-up payments	<input type="checkbox"/> Health or social club dues or initiation fees										
<input type="checkbox"/> Discretionary spending account	<input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef)										
b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain		1b									
2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked in line 1a?		2	X								
<p>3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.</p> <table border="0"> <tr> <td><input type="checkbox"/> Compensation committee</td> <td><input checked="" type="checkbox"/> Written employment contract</td> </tr> <tr> <td><input type="checkbox"/> Independent compensation consultant</td> <td><input checked="" type="checkbox"/> Compensation survey or study</td> </tr> <tr> <td><input checked="" type="checkbox"/> Form 990 of other organizations</td> <td><input checked="" type="checkbox"/> Approval by the board or compensation committee</td> </tr> </table>				<input type="checkbox"/> Compensation committee	<input checked="" type="checkbox"/> Written employment contract	<input type="checkbox"/> Independent compensation consultant	<input checked="" type="checkbox"/> Compensation survey or study	<input checked="" type="checkbox"/> Form 990 of other organizations	<input checked="" type="checkbox"/> Approval by the board or compensation committee		
<input type="checkbox"/> Compensation committee	<input checked="" type="checkbox"/> Written employment contract										
<input type="checkbox"/> Independent compensation consultant	<input checked="" type="checkbox"/> Compensation survey or study										
<input checked="" type="checkbox"/> Form 990 of other organizations	<input checked="" type="checkbox"/> Approval by the board or compensation committee										
4 During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:											
a Receive a severance payment or change-of-control payment?		4a	X								
b Participate in, or receive payment from, a supplemental nonqualified retirement plan?		4b	X								
c Participate in, or receive payment from, an equity-based compensation arrangement?		4c	X								
If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.											
Only section 501(c)(3) and 501(c)(4) organizations must complete lines 5-9.											
5 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:											
a The organization?		5a	X								
b Any related organization?		5b	X								
If "Yes" to line 5a or 5b, describe in Part III.											
6 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:											
a The organization?		6a	X								
b Any related organization?		6b	X								
If "Yes" to line 6a or 6b, describe in Part III.											
7 For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III											
7		7	X								
8 Were any amounts reported in Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III											
8		8	X								
9 If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?											
9		9									

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

Schedule J (Form 990) 2013

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
- ▶ Attach to Form 990.
- ▶ Information about Schedule M (Form 990) and its instructions is at www.irs.gov/form990.

Name of the organization

HYDROCEPHALUS ASSOCIATION

Employer identification number

94-3000301

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	X	4	100,913.	MARKET QUOTATION
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 Acknowledgement

29

	Yes	No
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?		X
b If "Yes," describe the arrangement in Part II.		
31 Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?	X	
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
b 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.		

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

Schedule M (Form 990) (2013)

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 990-EZ 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

HYDROCEPHALUS ASSOCIATION

Employer identification number

94-3000301

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

**RAISE AWARENESS AND FUND INNOVATIVE HIGH IMPACT RESEARCH TO PREVENT,
TREAT, AND ULTIMATELY CURE HYDROCEPHLAUS.**

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:

**PROPOSAL MR ELASTOGRAPHY: A NONINVASIVE TOOL FOR THE MANAGEMENT OF
SHUNTED PEDIATRIC HYDROCEPHALUS. DR. WAGSHUL WILL UTILIZE THIS
NONINVASIVE MRI-BASED TECHNIQUE TO SEE IF BRAIN COMPLIANCE CAN HELP
DETERMINE THE BEST TREATMENT OPTION FOR PEDIATRIC HYDROCEPHALIC
PATIENTS. THE GRANT IS FOR \$600,000 OVER 3 YEARS.**

**DR. WAGSHUL IS AN ASSOCIATE PROFESSOR IN THE DEPARTMENT OF RADIOLOGY AT
ALBERT EINSTEIN COLLEGE OF MEDICINE. HE RECEIVED A B.A. IN PHYSICS FROM
RUTGERS UNIVERSITY AND A PHD IN PHYSICS FROM HARVARD UNIVERSITY. HE
COMPLETED A POSTDOCTORAL FELLOWSHIP AT THE NATIONAL INSTITUTE FOR
STANDARDS AND TECHNOLOGY.**

**HA AWARDED A SECOND GRANT TO TIMOTHY VOGEL, MD, OF CINCINNATI
CHILDREN'S HOSPITAL. DR. VOGEL'S PROPOSAL, THE ROLE OF NEURAL
PROGENITOR CELLS IN NEONATAL HYDROCEPHALUS, FOCUSES ON CILIA, OR
HAIR-LIKE STRUCTURES ON THE SURFACE OF NEURON PROGENITOR CELLS (NPCS)
IN THE BRAIN THAT CONTRIBUTE TO CSF MOVEMENT. HE WILL BE EXPLORING HOW
DEFECTS IN CILIA MOTILITY CONTRIBUTE TO THE DEVELOPMENT OF NEONATAL
HYDROCEPHALUS. THE GRANT IS FOR \$400,000 OVER 3 YEARS.**

**DR. VOGEL IS A PEDIATRIC NEUROSURGEON AND ASSISTANT PROFESSOR OF
PEDIATRIC NEUROSURGERY AND DEVELOPMENTAL BIOLOGY AT CINCINNATI
CHILDREN'S HOSPITAL MEDICAL CENTER. HE HOLDS A B.A. IN CHEMISTRY FROM
PRINCETON UNIVERSITY AND AN MD FROM COLUMBIA UNIVERSITY COLLEGE OF**

Name of the organization

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PHYSICIANS AND SURGEONS.

THE SUCCESS OF THE HCRN PROVIDED THE CATALYST FOR ESTABLISHING AN ADULT HYDROCEPHALUS CLINICAL RESEARCH NETWORK (AHCN). IN 2012, HA BEGAN WORKING WITH DISTINGUISHED ADULT HYDROCEPHALUS RESEARCHERS INCLUDING NEUROSURGEONS, NEUROLOGISTS AND NEUROPSYCHOLOGISTS TO ESTABLISH THE NETWORK. THE GOALS OF THE ADULT NETWORK ARE TO IMPROVE THE LIVES OF ADULTS WITH HYDROCEPHALUS, RAISE AWARENESS OF THE CONDITION AND TACKLE THE UNIQUE ISSUES TRANSITIONAL PATIENTS, ADULT CONGENITAL PATIENTS AND OTHER ADULT-ONSET PATIENTS FACE.

FIVE SITES WERE SELECTED AND PROGRESS WAS MADE THROUGHOUT 2013 TO DEVELOP ESSENTIAL DATA ELEMENTS AND PROTOCOLS FOR THE NETWORK. THE FIVE PARTICIPATING RESEARCHERS AND SITES IN THE NETWORK INCLUDE: MARK HAMILTON, MD, OF THE UNIVERSITY OF CALGARY; HEATHER KATZEN, PHD, OF THE UNIVERSITY OF MIAMI; PETRA KLINGE, MD, OF BROWN UNIVERSITY; MARK LUCIANO, MD, PHD, OF CLEVELAND CLINIC; NORMAN RELKIN, MD, PHD, OF WEILL CORNELL MEDICAL COLLEGE; AND MICHAEL WILLIAMS, MD, OF THE SANDRA AND MALCOLM BERMAN BRAIN & SPINE INSTITUTE.

DR. JOHN KESTLE, CO-FOUNDER OF THE PEDIATRIC-FOCUSED HCRN, ASSISTED IN THE EFFORT TO ESTABLISH AHCN, BRINGING HIS RICH HISTORY IN HYDROCEPHALUS RESEARCH TO BENEFIT THE COLLABORATION. THE DEVELOPMENT OF THE ADULT NETWORK IS ESSENTIAL FOR HA'S MISSION TO IMPROVE THE LIVES OF ALL PEOPLE WITH HYDROCEPHALUS. THE ADULT NETWORK WILL INCREASE IN IMPORTANCE AS PEDIATRIC PATIENTS TRANSITION TO ADULTHOOD AND AWARENESS OF ADULT-ONSET HYDROCEPHALUS INCREASES.

THE PEDIATRIC-FOCUSED HYDROCEPHALUS CLINICAL RESEARCH NETWORK (HCRN) EXPANDED ITS NETWORK FROM SEVEN TO NINE CENTERS WITH THE ADDITIONS OF VANDERBILT UNIVERSITY AND THE UNIVERSITY OF BRITISH COLUMBIA.

INITIALLY, THE TWO CENTERS FOCUSED ON ADDING PATIENTS TO THE HCRN

Name of the organization

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REGISTRY AND PARTICIPATING IN THE HCRN QUALITY IMPROVEMENT STUDY FOR POST-SURGICAL INFECTIONS. THEY ARE NOW COMPLETELY INCORPORATED INTO THE HCRN. DR. WELLONS IS HEADING THE CENTER AT VANDERBILT AND CONTINUES TO BE THE LEAD PRINCIPAL INVESTIGATOR ON THE STUDY OF POST HEMORRHAGIC HYDROCEPHALUS, WHICH IS NEARING THE COMPLETION OF ITS ACCRUAL OF PATIENTS. DR. DOUG COCHRANE IS HEADING THE CENTER AT THE UNIVERSITY OF BRITISH COLUMBIA. IN ADDITION TO EXPANDING TO NINE CENTERS, THE HCRN HAS BEEN BUSY PUBLISHING THREE PAPERS IN 2013.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:

AND OTHER EXPERTS WORKING IN THE FIELD OF HYDROCEPHALUS.

WE HOSTED OUR FIRST WEBINAR, "WHAT IF IT ISN'T ALZHEIMER'S OR PARKINSON'S?" PRESENTED BY DR. MICHAEL WILLIAMS, DURING HYDROCEPHALUS AWARENESS MONTH IN SEPTEMBER. THIS WEBINAR WAS TARGETED TO INDIVIDUALS WHO HAVE BEEN DIAGNOSED WITH NORMAL PRESSURE HYDROCEPHALUS, CAREGIVERS OF OLDER ADULTS, MEDICAL PROFESSIONALS, NURSING HOME STAFF AND THOSE WHO HAVE BEEN TREATED FOR PARKINSON'S, ALZHEIMER'S OR DEMENTIA.

IN 2013, WE RESTRUCTURED OUR SUPPORT GROUPS TO SERVE AS BROADER-BASED COMMUNITY NETWORKS. THE NETWORKS PROVIDE LOCALIZED SUPPORT, EDUCATION AND EMPOWERMENT BY HOSTING EDUCATIONAL EVENTS, SUPPORT GROUP MEETINGS, ADVOCACY ACTIVITIES AND OTHER GATHERINGS THAT ENABLE INDIVIDUALS AND FAMILIES TO THRIVE. THEY CONSIST OF 39 NETWORKS, WHICH HELD 80 EVENTS INVOLVING NEARLY 1,500 PARTICIPANTS. IN ADDITION, WE HAVE 25 ACTIVE VIRTUAL NETWORKS WITH ONLINE FACEBOOK GROUPS CONSISTING OF MORE THAN 1,200 MEMBERS. THESE CLOSED GROUPS ALLOW THOSE LIVING WITH HYDROCEPHALUS, AND THEIR LOVED ONES, TO CONNECT AND SHARE IN A PRIVATE FORUM IN THEIR OWN REGION AS WELL AS THROUGHOUT THE WORLD.

EACH YEAR THE HYDROCEPHALUS ASSOCIATION PRESENTS A RESIDENT'S PRIZE

Name of the organization

HYDROCEPHALUS ASSOCIATION

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AWARD TO ENCOURAGE YOUNG DOCTORS TO FOCUS THEIR RESEARCH EFFORTS ON ADVANCING THE TREATMENT AND CARE OF INDIVIDUALS WITH HYDROCEPHALUS. IT IS AWARDED EACH YEAR TO THE MOST PROMISING HYDROCEPHALUS-RELATED RESEARCH PAPER PRESENTED BY A NEUROSURGICAL RESIDENT AT THE PEDIATRIC SECTION MEETING OF THE AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS (AANS)/CONGRESS OF NEUROLOGICAL SURGEONS (CNS) IN TORONTO, CANADA. SINCE THE HYDROCEPHALUS ASSOCIATION'S SCHOLARSHIP PROGRAM WAS ESTABLISHED IN 1994, WE HAVE AWARDED 103 SCHOLARSHIPS TO DESERVING FUTURE LEADERS OF OUR COMMUNITY. THIS YEAR, WE WERE ABLE TO OFFER NINE EDUCATIONAL SCHOLARSHIPS TO YOUNG ADULTS LIVING WITH HYDROCEPHALUS WHO HAVE EXHIBITED PROMISING LEADERSHIP SKILLS AND ARE INVOLVED IN THEIR COMMUNITIES. DESPITE THE TREMENDOUS CHALLENGES AND OBSTACLES THEY FACE, THESE STUDENTS CONTINUE TO EXCEL IN THE CLASSROOM, VOLUNTEER AND GIVE BACK TO THEIR COMMUNITIES, AND INSPIRE THEIR PEERS AND ALL OF US. THESE AWARDS WERE MADE POSSIBLE THROUGH THE SUPPORT OF THE FOLLOWING ENDOWED SCHOLARSHIP FUNDS: GERARD SWARTZ FUDGE MEMORIAL SCHOLARSHIP FUND, MORRIS L. AND REBECCA ZISKIND MEMORIAL SCHOLARSHIP FUND, ANTHONY ABBENE SCHOLARSHIP FUND, THE JUSTIN SCOT ALSTON MEMORIAL SCHOLARSHIP FUND, THE MARIO J. TOCCO HYDROCEPHALUS FOUNDATION SCHOLARSHIP FUND AND THE GIAVANNA MARIE MELOMO MEMORIAL SCHOLARSHIP FUND.

FOR THE SECOND YEAR, WE ALSO AWARDED FIVE ADDITIONAL SCHOLARSHIPS THROUGH OUR TEENS TAKE CHARGE (TTC) PROGRAM. TTC'S SCHOLARSHIP AWARDS WERE MADE POSSIBLE THROUGH THE CONTINUED SUPPORT OF THE MEDTRONIC FOUNDATION AND ALL THE INDIVIDUALS WHO HELD EVENTS AND CONTRIBUTED TO THE PROGRAM.

THE TEENS TAKE CHARGE (TTC) PROGRAM CONTINUES TO FACILITATE AN ACTIVE ONLINE COMMUNITY OF MORE THAN 1,500 TEENS AND YOUNG ADULTS AFFECTED BY HYDROCEPHALUS, AND THEIR SIBLINGS. THIS FORUM PROVIDES AN OPPORTUNITY

Name of the organization

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FOR YOUNG ADULTS TO OPENLY SHARE THEIR JOURNEY AND PROVIDE PEER-TO-PEER SUPPORT, ENCOURAGEMENT AND ADVICE. TTC MEMBERS ARE INVOLVED IN VARIOUS FUNDRAISING AND AWARENESS ACTIVITIES, FROM PRESENTING AT SCHOOL ASSEMBLIES AND HOLDING CLASSROOM DISCUSSIONS ON HYDROCEPHALUS, TO TAKING PART IN LOCAL PARADES AND REPRESENTING THE PROGRAM AT OUR WALK EVENTS. IN ADDITION, TTC'S ADVISORY COUNCIL AND MEMBERS PUBLISH ARTICLES AND SHARE THEIR PERSONAL STORIES OF ENCOURAGEMENT THAT ARE POSTED ON OUR WEBSITE AND VARIOUS SOCIAL MEDIA PLATFORMS TO INSPIRE YOUTHS LIVING WITH THIS CONDITION.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:

THAT CONGRESS: UNDERSTANDS THE BREADTH AND DEPTH OF IMPACT OF HYDROCEPHALUS ON OUR PEOPLE; PRIORITIZES FUNDING HYDROCEPHALUS RESEARCH FOR IMPROVED TREATMENTS AND CURES; AND SUPPORTS THOSE AFFECTED BY HYDROCEPHALUS WITH APPROPRIATE PROGRAMS.

COALITION BUILDING: HA WORKS WITH A NUMBER OF NATIONAL HEALTH ADVOCACY GROUPS TO PROMOTE THE IMPORTANCE OF FEDERALLY SPONSORED RESEARCH. WE JOINED RESEARCH!AMERICA, THE NATION'S LARGEST NOT-FOR-PROFIT PUBLIC EDUCATION AND ADVOCACY ALLIANCE WORKING TO MAKE RESEARCH TO IMPROVE HEALTH A HIGHER NATIONAL PRIORITY. THROUGH THIS COALITION, WE URGED CONGRESS AND THE ADMINISTRATION TO INCREASE FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH), CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ), FOOD AND DRUG ADMINISTRATION (FDA) AND NATIONAL SCIENCE FOUNDATION (NSF) AT LEVELS THAT KEEP PACE WITH SCIENTIFIC OPPORTUNITY. WE ALSO ADVOCATED FOR FEDERAL FUNDING FOR GLOBAL HEALTH RESEARCH AND A LEGISLATIVE AND REGULATORY CLIMATE THAT STIMULATES GROWTH IN INDUSTRY RESEARCH AND DEVELOPMENT. IN ADDITION, HA WAS ACTIVE IN ADVOCACY MEETINGS AND

Name of the organization

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SIGN-ON LETTERS PUT TOGETHER AS PART OF THE NATIONAL HEALTH COUNCIL (NHC), THE AMERICAN BRAIN COALITION (ABC), THE RARE DISEASE LEGISLATIVE ADVOCATES (RDLA), AND THE NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD). TOPICS HAVE INCLUDED THE IMPLEMENTATION OF THE AFFORDABLE CARE ACT, THE EFFECTS OF SEQUESTRATION ON RESEARCH FUNDING, AND THE ORPHAN DRUG ACT.

CONGRESSIONAL DIRECTED MEDICAL RESEARCH: HA ADVOCATED FOR THE INCLUSION OF HYDROCEPHALUS ON THE LIST OF CONDITIONS ELIGIBLE FOR FUNDING UNDER THE DEPARTMENT OF DEFENSE'S CONGRESSIONAL DIRECTED MEDICAL RESEARCH PROGRAMS (CDMRP). GREAT STRIDES WERE MADE TO EDUCATE THE HOUSE AND SENATE SPENDING AND AUTHORIZING COMMITTEES THAT ALLOCATE MONEY FOR FEDERAL HEALTH CARE RESEARCH. HA REACHED OUT TO HEALTH AND DEFENSE APPROPRIATORS AND AUTHORIZERS TO HELP INCREASE FUNDING FOR HYDROCEPHALUS RESEARCH AT NIH AND TO CREATE A NEW FUNDING STREAM FOR HYDROCEPHALUS RESEARCH THROUGH THE DEPARTMENT OF DEFENSE'S PEER REVIEWED MEDICAL RESEARCH PROGRAM (PRMRP). WE WERE SUCCESSFUL IN GAINING SUPPORT ON THE SENATE APPROPRIATIONS SIDE FOR THE HYDROCEPHALUS SPECIFIC LANGUAGE THAT REPRESENTATIVE ANDREWS INCLUDED IN THE NATIONAL DEFENSE AUTHORIZATION ACT. UNFORTUNATELY, DUE TO PARTISAN BATTLES WITHIN CONGRESS OVER OTHER ISSUES, THE LANGUAGE INCLUDED IN A BILL PASSED BY THE HOUSE OF REPRESENTATIVES WAS NOT INCLUDED IN THE FINAL DOD APPROPRIATIONS BILL PASSED BY A CONFERENCE COMMITTEE OF BOTH THE HOUSE AND SENATE. THE ASSOCIATION CONTINUES TO PURSUE THIS INITIATIVE AT PRESENT.

NATIONAL INSTITUTES OF HEALTH PARTNERSHIP: THE NATIONAL INSTITUTES OF HEALTH (NIH) NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS) HOSTED THEIR ANNUAL NONPROFIT FORUM. THE FORUM, "PROGRESS THROUGH PARTNERSHIP," EMPHASIZED THE ROLE NONPROFITS PLAY IN LINKING

Name of the organization

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SCIENTISTS AT NINDS WITH THE PATIENT COMMUNITY FOR BETTER RESEARCH OUTCOMES. PAUL GROSS, HA BOARD MEMBER AND MEMBER OF THE NINDS ADVISORY COUNCIL, SERVED ON THE PLANNING COMMITTEE THAT HELPED BUILD THE AGENDA FOR THE EVENT. REPRESENTATIVES FROM OVER 80 NONPROFIT ORGANIZATIONS HAD THE OPPORTUNITY TO LISTEN TO AND INTERACT WITH KEY NINDS OFFICIALS, INCLUDING DR. STORY LANDIS, DIRECTOR OF NINDS, AND DR. KATHY HUDSON, DEPUTY DIRECTOR FOR SCIENCE, OUTREACH AND POLICY AT NIH.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

HYDROCEPHALUS CONFERENCE

EXPENSES \$ 24,541. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 1:

EXPLANATION: ACCORDING TO OUR BYLAWS, THE EXECUTIVE COMMITTEE, UNLESS LIMITED IN A RESOLUTION OF THE BAORD, SHALL HAVE AND MAY EXERCISE ALL OF THE AUTHORITY OF THE BOARD IN THE MANAGEMENT OF THE BUSINESS AND AFFAIRS OF THE CORPORATION BETWEEN MEETINGS OF THE BOARD. THE EXECUTIVE COMMITTEE IS COMPOSED OF 1) BARRETT O'CONNOR, CHAIRMAN 2) CRAIG BROWN, SENIOR VICE CHAIRMAN 3) DAVID BROWDY, VICE CHAIR 4) ASEEM CHANDRA, VICE CHAIR 5) RICK SMITH, TREASURER 6) PAUL GROSS, SECRETARY/PAST CHAIR. EVERY EXECUTIVE COMMITTEE MEMBER IS ON THE GOVERNING BOARD.

FORM 990, PART VI, SECTION B, LINE 11:

EXPLANATION: ALL BOARD MEMBERS RECEIVE AN ELECTRONIC OR PAPER COPY OF THE IRS FORM 990 PRIOR TO ITS SUBMISSION. BOARD MEMBERS MUST SUBMIT ANY QUESTIONS OR CHANGES TO THE CHIEF EXECUTIVE OFFICER, WHO SUBMITS THE CHANGES TO THE TAX PREPARER.

Name of the organization HYDROCEPHALUS ASSOCIATION	Employer identification number 94-3000301
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FORM 990, PART VI, SECTION B, LINE 12C:

EXPLANATION: EACH YEAR BOARD MEMBERS GET A COPY OF THE CONFLICT OF INTEREST POLICY AND A DISCLOSURE FORM TO FILL OUT WITH DETAILS OF ANT ANY POSSIBLE CONFLICTS THAT MAY EXIST.

FORM 990, PART VI, SECTION B, LINE 15A:

EXPLANATION: THE PROCESS FOR DETERMING THE COMPENSATION FOR THE CHIEF EXECUTIVE OFFICER (WHO IS ALSO IN CHARGE OF FINANCIAL MANAGEMENT OF THE ORGANIZATION) POSITION INCLUDES THE FOLLOWING STEPS:

- 1) THE BOARD CHAIR AND CHIEF EXECUTIVE OFFICER EACH COLLECT COMPARABLE SALARY INFORMATION (E.G., SALARY STUDIES).
 - 2) THE SALARY COMPARISON INFORMATION IS FORWARDED TO THE TREASURER WHO DOCUMENTS FINDINGS FROM THE DATA COLLECTED.
 - 3) THE TREASURER MAKES A RECOMMENDATION FOR CEO COMPENSATION TO THE FULL BOARD.
 - 4) BOARD MEMBERS (WITHOUT A CONFLICT OF INTEREST) VOTE ON THE RECOMMENDATION BY THE TREASURER FOR PROPOSED CEO COMPENSATION, AND A RECORD OF THE VOTE IS RECORDED IN BOARD MINUTES.
- OTHER SALARIES OF SENIOR MANAGERS ARE BENCHMARKED USING CURRENT SALARY SURVEY DATA; OUR GOAL IS TO PROVIDE THE MEDIAN SALARY PROVIDED BY SIMILAR ORGANIZATIONS. THIS PROCESS IS FOLLOWED ON A PERIODIC BASIS FOR THE CEO, BASED ON CONTRACT RENEWAL DATES.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:
AL, AK, AR, CA, CT, FL, GA, IL, KS, KY, ME, MD, MA, MI, MN, MS, NH, NJ, NM, NY, NC, OH, OK, OR, PA, RI, SC, TN, UT, VA, WV, WI, CO, WA

FORM 990, PART VI, SECTION C, LINE 19:

Name of the organization

HYDROCEPHALUS ASSOCIATION

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EXPLANATION: THE ORGANIZATION'S GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS ARE AVAILABLE TO THE PUBLIC AT THE ORGANIZATION'S OFFICE UPON REQUEST.

FORM 990, PART IX, LINE 24E, ALL OTHER FUNCTIONAL EXPENSES:

EMPLOYEE EDUCATION:

PROGRAM SERVICE EXPENSES	87.
MANAGEMENT AND GENERAL EXPENSES	4,319.
FUNDRAISING EXPENSES	426.
TOTAL EXPENSES	4,832.

MISCELLANOUES EXPENSES:

PROGRAM SERVICE EXPENSES	1,239.
MANAGEMENT AND GENERAL EXPENSES	1,925.
FUNDRAISING EXPENSES	1,198.
TOTAL EXPENSES	4,362.

PRIZE/AWARD:

PROGRAM SERVICE EXPENSES	294.
MANAGEMENT AND GENERAL EXPENSES	0.
FUNDRAISING EXPENSES	282.
TOTAL EXPENSES	576.

TOTAL OTHER EXPENSES ON FORM 990, PART IX, LINE 24E, COL A	9,770.
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FORM 990 PART XI - 2C

EXPLANATION: THE AUDIT COMMITTEE SELECTS AND OVERSEES AN INDEPENDENT ACCOUNTING FIRM TO CONDUCT THE AUDIT. NO CHANGE IN THE SELECTION METHOD OCCURRED THIS YEAR.

Name of the organization

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Employer identification number

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• If you are filing for an **Additional (Not Automatic) 3-Month Extension**, complete only **Part II** and check this box **X**

Note. Only complete Part II if you have already been granted an automatic 3-month extension on a previously filed Form 8868.

• If you are filing for an **Automatic 3-Month Extension**, complete only **Part I** (on page 1).

Part II Additional (Not Automatic) 3-Month Extension of Time. Only file the original (no copies needed).

Enter filer's identifying number, see instructions

Type or print	Name of exempt organization or other filer, see instructions. HYDROCEPHALUS ASSOCIATION	Employer identification number (EIN) or 94-3000301
File by the due date for filing your return. See instructions.	Number, street, and room or suite no. If a P.O. box, see instructions. 4340 EAST WEST HIGHWAY, NO. 905	Social security number (SSN)
	City, town or post office, state, and ZIP code. For a foreign address, see instructions. BETHESDA, MD 20814	

Enter the Return code for the return that this application is for (file a separate application for each return) 01

Application Is For	Return Code	Application Is For	Return Code
Form 990 or Form 990-EZ	01		
Form 990-BL	02	Form 1041-A	08
Form 4720 (individual)	03	Form 4720 (other than individual)	09
Form 990-PF	04	Form 5227	10
Form 990-T (sec. 401(a) or 408(a) trust)	05	Form 6069	11
Form 990-T (trust other than above)	06	Form 8870	12

STOP! Do not complete Part II if you were not already granted an automatic 3-month extension on a previously filed Form 8868.

DAWN MANCUSO

• The books are in the care of **4340 EAST WEST HIGHWAY, NO. 905 - BETHESDA, MD 20814**
Telephone No. **(301) 201-3811** Fax No. _____

• If the organization does not have an office or place of business in the United States, check this box

• If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) _____. If this is for the whole group, check this box . If it is for part of the group, check this box and attach a list with the names and EINs of all members the extension is for.

4 I request an additional 3-month extension of time until **NOVEMBER 15, 2014.**

5 For calendar year **2013**, or other tax year beginning _____, and ending _____.

6 If the tax year entered in line 5 is for less than 12 months, check reason: Initial return Final return
 Change in accounting period

7 State in detail why you need the extension
ADDITIONAL TIME IS NEEDED TO GATHER SUFFICIENT INFORMATION IN ORDER TO FILE A COMPLETE INFORMATIONAL RETURN.

8a If this application is for Forms 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.	8a	\$	0.
8b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit and any amount paid previously with Form 8868.	8b	\$	0.
8c Balance due. Subtract line 8b from line 8a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.	8c	\$	0.

Signature and Verification must be completed for Part II only.

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

Signature Title **CHIEF EXECUTIVE OFFICER** Date