

**Return of Organization Exempt From Income Tax**  
Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

OMB No. 1545-0047  
**2012**  
Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

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

**A For the 2012 calendar year, or tax year beginning and ending**

**B** Check if applicable:  
 Address change  
 Name change  
 Initial return  
 Terminated  
 Amended return  
 Application pending

**C Name of organization**  
**HYDROCEPHALIS ASSOCIATION**  
 Doing Business As  
 Number and street (or P.O. box if mail is not delivered to street address) Room/suite  
**4340 EAST WEST HIGHWAY 905**  
 City, town, or post office, state, and ZIP code  
**BETHESDA, MD 20814**  
**F Name and address of principal officer: DAWN MANCUSO**  
**SAME AS C ABOVE**

**D Employer identification number**  
**94-3000301**

**E Telephone number**  
**(301) 202-3811**

**G Gross receipts \$** **2,492,617.**

**H(a) Is this a group return for affiliates?**  Yes  No  
**H(b) Are all affiliates included?**  Yes  No  
 If "No," attach a list. (see instructions)

**H(c) Group exemption number** ▶

**I Tax-exempt status:**  501(c)(3)  501(c) ( ) ◀ (insert no.)  4947(a)(1) or  527

**J Website:** ▶ **WWW.HYDROASSOC.ORG**

**K Form of organization:**  Corporation  Trust  Association  Other ▶

**L Year of formation:** **1986** **M State of legal domicile:** **CA**

**Part I Summary**

<b>Activities &amp; Governance</b>	1 Briefly describe the organization's mission or most significant activities: <b>THE HYDROCEPHALUS ASSOCIATION SEEKS TO ELIMINATE THE CHALLENGES OF HYDROCEPHALUS BY STIMULATING</b>		
	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) ..... <b>3</b> <b>17</b>	
	4	Number of independent voting members of the governing body (Part VI, line 1b) ..... <b>4</b> <b>16</b>	
	5	Total number of individuals employed in calendar year 2012 (Part V, line 2a) ..... <b>5</b> <b>15</b>	
	6	Total number of volunteers (estimate if necessary) ..... <b>6</b> <b>1200</b>	
	7a	Total unrelated business revenue from Part VIII, column (C), line 12 ..... <b>7a</b> <b>0.</b>	
7b	Net unrelated business taxable income from Form 990-T, line 34 ..... <b>7b</b> <b>0.</b>		
<b>Revenue</b>	8	Contributions and grants (Part VIII, line 1h) ..... <b>1,689,904.</b> <b>2,247,530.</b>	
	9	Program service revenue (Part VIII, line 2g) ..... <b>0.</b> <b>76,921.</b>	
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d) ..... <b>10,348.</b> <b>10,774.</b>	
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) ..... <b>-96,616.</b> <b>-121,354.</b>	
	12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) ..... <b>1,603,636.</b> <b>2,213,871.</b>	
	<b>Expenses</b>	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3) ..... <b>487,827.</b> <b>111,122.</b>
		14	Benefits paid to or for members (Part IX, column (A), line 4) ..... <b>0.</b> <b>0.</b>
		15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) ..... <b>717,852.</b> <b>820,867.</b>
		16a	Professional fundraising fees (Part IX, column (A), line 11e) ..... <b>14,000.</b> <b>31,200.</b>
		16b	Total fundraising expenses (Part IX, column (D), line 25) ▶ <b>523,201.</b>
		17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) ..... <b>585,336.</b> <b>875,313.</b>
		18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) ..... <b>1,805,015.</b> <b>1,838,502.</b>
19		Revenue less expenses. Subtract line 18 from line 12 ..... <b>-201,379.</b> <b>375,369.</b>	
<b>Net Assets or Fund Balances</b>	20	Total assets (Part X, line 16) ..... <b>1,215,491.</b> <b>1,652,061.</b>	
	21	Total liabilities (Part X, line 26) ..... <b>143,095.</b> <b>194,607.</b>	
	22	Net assets or fund balances. Subtract line 21 from line 20 ..... <b>1,072,396.</b> <b>1,457,454.</b>	

**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 **11/14/13**  
 ▶ Type or print name and title

**Paid Preparer Use Only**  
 Print/Type preparer's name **HYDEH GHAFFARI** Preparer's signature **H. Ghaffari** Date **11/15/13** Check if self-employed  PTIN **P01228587**  
 Firm's name ▶ **GHAFFARI ACCOUNTANCY INC.** Firm's EIN ▶ **80-0842045**  
 Firm's address ▶ **1330 BROADWAY, SUITE 430 OAKLAND, CA 94612** Phone no. **510-834-6542**

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: THE HYDROCEPHALUS ASSOCIATION SEEKS TO ELIMINATE THE CHALLENGES OF HYDROCEPHALUS BY STIMULATING INNOVATIVE RESEARCH AND PROVIDING SUPPORT AND EDUCATION FOR INDIVIDUALS, FAMILIES AND PROFESSIONALS.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [X] Yes [ ] 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 \$ 283,392. including grants of \$ 9,521.) (Revenue \$ 11,220.) PUBLIC SUPPORT AND EDUCATION

THE HYDROCEPHALUS ASSOCIATION PROVIDES DIRECT PUBLIC EDUCATION AND SUPPORT BY: ORGANIZING AND SUPPORTING 32 ACTIVE SUPPORT GROUPS IN 25 STATES, HOLDING 61 SUPPORT GROUP MEETINGS FOR PATIENTS AND FAMILIES DURING 2012; HOSTING THE NATIONAL HYDROCEPHALUS CONFERENCE FOR 400 PATIENTS AND FAMILY MEMBERS THAT WAS HELD IN JUNE 2012 IN BETHESDA, MARYLAND; AWARDING SCHOLARSHIPS TO 10 STUDENTS WITH HYDROCEPHALUS WHO ARE PURSUING POST-SECONDARY EDUCATION; PROVIDING DIRECT SUPPORT TO TENS OF THOUSANDS OF PATIENTS AND FAMILIES BY ANSWERING QUESTIONS AND PROVIDING REFERRALS VIA TELEPHONE, EMAIL AND THROUGH SOCIAL MEDIA CHANNELS; AWARDING A SPECIAL PRIZE TO A PROMISING MEDICAL RESIDENT INTERESTED IN THE CARE OF HYDROCEPHALUS PATIENTS; AND PUBLISHING A FULL

4b (Code: ) (Expenses \$ 273,367. including grants of \$ ) (Revenue \$ 59,985.) HYDROCEPHALUS CONFERENCE

THE NATIONAL HYDROCEPHALUS CONFERENCE WAS HELD JUNE 27 - JULY 1, 2012 IN BETHESDA, MARYLAND. OVER 400 PATIENTS AND FAMILY MEMBERS PARTICIPATED IN THIS PATIENT-CENTERED EVENT, WHERE THEY HEARD PRESENTATIONS IN OVER 40 WORKSHOPS AND LEARNED THE LATEST IN TREATMENT ADVANCES FROM LEARNED MEDICAL PROFESSIONALS. THEY ALSO LEARNED LIFE SKILLS AND HOW TO ADVOCATE FOR THEIR CARE THROUGH FACILITATED GROUP DISCUSSIONS. THE CONFERENCE PROVIDED TOOLS AND CONNECTIONS TO ADDRESS THE MEDICAL, EDUCATIONAL AND SOCIAL CHALLENGES OF LIVING WITH HYDROCEPHALUS AND TO PROVIDE THE OPPORTUNITY FOR AN ENJOYABLE GET-TOGETHER. THIS EVENT EMPOWERED THOSE IN ATTENDANCE TO UNDERSTAND, SEEK OUT, AND PUT INTO PLACE CARE PROGRAMS AND SERVICES THAT MEET THEIR

4c (Code: ) (Expenses \$ 226,673. including grants of \$ 96,276.) (Revenue \$ 0.) RESEARCH

RESEARCH PROGRAMS ARE ONE OF THE KEY MISSION AREAS OF FOCUS FOR THE HYDROCEPHALUS ASSOCIATION. HA'S 2012 CHAIRMAN OF THE BOARD, PAUL GROSS, WAS NAMED TO THE ADVISORY COUNCIL OF THE NIH'S NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS), THE COUNCIL WITHIN NIH THAT OVERSEES HYDROCEPHALUS RESEARCH. THE ASSOCIATION HELD A MEETING WITH THE TRANS-NIH HYDROCEPHALUS WORKING GROUP, A GATHERING OF KEY PERSONNEL FROM A VARIETY OF INSTITUTES WITHIN NIH (SUCH AS NINDS, NATIONAL INSTITUTE OF BIOMEDICAL IMAGING AND BIOENGINEERING (NIBIB), AND THE EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD), AMONG OTHERS) THAT HAVE AN INTEREST IN HYDROCEPHALUS.

4d Other program services (Describe in Schedule O.) (Expenses \$ 209,258. including grants of \$ 5,325.) (Revenue \$ 18,315.)

4e Total program service expenses 992,690.

**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	<b>Section 501(c)(3) organizations.</b> 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 assistance to any organization or entity located outside the United States? <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 assistance to individuals located outside the United States? <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 f</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?		X

**Part IV Checklist of Required Schedules** (continued)

		Yes	No
21	Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> .....	X	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i> .....	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 25</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	<b>Section 501(c)(3) and 501(c)(4) organizations.</b> 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	Was a loan to or by a current or former officer, director, trustee, key employee, highest compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i> .....		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	<b>Section 501(c)(3) organizations.</b> 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? .....	X	

**Note.** All Form 990 filers are required to complete Schedule O .....

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Form with questions 1a through 14b regarding tax compliance, including employee counts, foreign accounts, and charitable contributions.

**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 to any question in this Part VI

**Section A. Governing Body and Management**

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year ..... If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O.		
	1a	17	
b	Enter the number of voting members included in line 1a, above, who are independent .....		
	1b	16	
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
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? .....		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body? .....	X	
b	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.)

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

**Section C. Disclosure**

- 17 List the states with which a copy of this Form 990 is required to be filed **MD, CA**
- 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  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) 202-3811**  
**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 to any question in this Part VII

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, 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) PAUL GROSS CHAIR	12.00	X		X				0.	0.	0.
(2) RAYMOND MOSER SENIOR VICE CHAIRMAN	2.00	X		X				0.	0.	0.
(3) BARRETT O'CONNOR VICE CHAIR	2.00	X		X				0.	0.	0.
(4) CRAIG BROWN TREASURER	2.00	X		X				0.	0.	0.
(5) DEBORAH PHILLIPS DIRECTOR	2.00	X						0.	0.	0.
(6) MARVIN SUSSMAN DIRECTOR	2.00	X						0.	0.	0.
(7) RALPH KISTLER DIRECTOR	2.00	X						0.	0.	0.
(8) DAVID BROWDY 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) ASEEM CHANDRA DIRECTOR	2.00	X						0.	0.	0.
(16) RICK SMITH INTERIM CEO/SECRETARY	2.00	X		X				0.	0.	0.
(17) RALPH KISTLER DIRECTOR	2.00	X						0.	0.	0.

**Part VII** Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees *(continued)*

(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			
(18) DAWN MANCUSO CEO	54.00			X				180,250.	0.	11,560.
<b>1b Sub-total</b>								180,250.	0.	11,560.
<b>c Total from continuation sheets to Part VII, Section A</b>								0.	0.	0.
<b>d Total (add lines 1b and 1c)</b>								180,250.	0.	11,560.

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization **1**

	Yes	No
3 Did the organization list any former officer, director, or trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual		X
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual	X	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person		X

**Section B. Independent Contractors**

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
NONE		

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization **0**



**Part VIII Statement of Revenue**

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

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a	Federated campaigns	1a					
	b	Membership dues	1b					
	c	Fundraising events	1c	1,054,912.				
	d	Related organizations	1d					
	e	Government grants (contributions)	1e	13,425.				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	1,179,193.				
	g	Noncash contributions included in lines 1a-1f: \$		135,879.				
	h	<b>Total.</b> Add lines 1a-1f		2,247,530.				
	Program Service Revenue	2 a	CONFERENCE FEES	Business Code 541900	76,921.	76,921.		
b								
c								
d								
e								
f		All other program service revenue						
g		<b>Total.</b> Add lines 2a-2f		76,921.				
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		13,640.			13,640.	
	4	Income from investment of tax-exempt bond proceeds						
	5	Royalties						
	6 a	Gross rents	(i) Real	(ii) Personal				
		b	Less: rental expenses					
		c	Rental income or (loss)					
		d	Net rental income or (loss)					
	7 a	Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
		b	Less: cost or other basis and sales expenses					
		c	Gain or (loss)					
		d	Net gain or (loss)			-2,866.		-2,866.
	8 a	Gross income from fundraising events (not including \$ 1,054,912. of contributions reported on line 1c). See Part IV, line 18	a		0.			
		b	Less: direct expenses	b	138,903.			
		c	Net income or (loss) from fundraising events		-138,903.			-138,903.
	9 a	Gross income from gaming activities. See Part IV, line 19	a					
b		Less: direct expenses	b					
c		Net income or (loss) from gaming activities						
10 a	Gross sales of inventory, less returns and allowances	a		16,647.				
	b	Less: cost of goods sold	b	4,965.				
	c	Net income or (loss) from sales of inventory		11,682.	11,682.			
Miscellaneous Revenue			Business Code					
11 a	OTHER INCOME	900099		5,949.	5,949.			
b	DISPOSAL OF FIXED ASSET	900099		-82.	-82.			
c								
d	All other revenue							
e	<b>Total.</b> Add lines 11a-11d			5,867.				
12	<b>Total revenue.</b> See instructions.			2,213,871.	94,470.	0.	-128,129.	

**Part IX Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

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	97,101.	97,101.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22	14,021.	14,021.		
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	191,810.	59,195.	88,534.	44,081.
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	507,246.	281,806.	142,994.	82,446.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	70,438.	32,095.	29,599.	8,744.
10 Payroll taxes	51,373.	25,994.	16,562.	8,817.
11 Fees for services (non-employees):				
a Management				
b Legal	3,550.		3,550.	
c Accounting	27,879.		27,879.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17	31,200.			31,200.
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.)	156,140.	68,817.	29,002.	58,321.
12 Advertising and promotion	295.	295.		
13 Office expenses	265,375.	57,995.	60,435.	146,945.
14 Information technology	35,108.	377.	27,871.	6,860.
15 Royalties				
16 Occupancy	64,927.	11,635.	44,694.	8,598.
17 Travel	146,642.	66,277.	35,640.	44,725.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	3,025.	3,025.		
20 Interest	1,007.		1,007.	
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	9,631.		9,631.	
23 Insurance	4,078.		4,078.	
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 <b>FOOD, MEALS &amp; CATERING</b>	125,542.	122,303.	3,028.	211.
b <b>MISCELLANEOUS EXPENSES</b>	27,814.	442.	26,829.	543.
c <b>EMPLOYEE EDUCATION</b>	4,300.	0.	4,300.	0.
d <b>SHARED COST ALLOCATION</b>	0.	151,312.	-233,022.	81,710.
e All other expenses				
<b>25 Total functional expenses.</b> Add lines 1 through 24e	<b>1,838,502.</b>	<b>992,690.</b>	<b>322,611.</b>	<b>523,201.</b>
<b>26 Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here  if following SOP 98-2 (ASC 958-720)

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year	
<b>Assets</b>	1	Cash - non-interest-bearing .....	295,750.	1	1,132,500.
	2	Savings and temporary cash investments .....	284,809.	2	
	3	Pledges and grants receivable, net .....	215,000.	3	76,500.
	4	Accounts receivable, net .....	1,544.	4	38,834.
	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 .....	10,680.	8	16,525.
	9	Prepaid expenses and deferred charges .....	26,185.	9	12,760.
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	78,523.		
	10b	Less: accumulated depreciation .....	25,906.		
	10c		28,498.	10c	52,617.
	11	Investments - publicly traded securities .....	348,019.	11	312,216.
	12	Investments - other securities. See Part IV, line 11 .....		12	
	13	Investments - program-related. See Part IV, line 11 .....		13	
	14	Intangible assets .....		14	
15	Other assets. See Part IV, line 11 .....	5,006.	15	10,109.	
16	<b>Total assets.</b> Add lines 1 through 15 (must equal line 34) .....	1,215,491.	16	1,652,061.	
<b>Liabilities</b>	17	Accounts payable and accrued expenses .....	121,773.	17	99,677.
	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 .....	21,322.	25	94,930.
	26	<b>Total liabilities.</b> Add lines 17 through 25 .....	143,095.	26	194,607.
<b>Net Assets or Fund Balances</b>	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 .....	763,927.	27	900,005.
	28	Temporarily restricted net assets .....	227,651.	28	476,331.
	29	Permanently restricted net assets .....	80,818.	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	<b>Total net assets or fund balances</b> .....	1,072,396.	33	1,457,454.	
34	<b>Total liabilities and net assets/fund balances</b> .....	1,215,491.	34	1,652,061.	

**Part XI Reconciliation of Net Assets**

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,213,871.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,838,502.
3	Revenue less expenses. Subtract line 2 from line 1	3	375,369.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,072,396.
5	Net unrealized gains (losses) on investments	5	9,689.
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	1,457,454.

**Part XII Financial Statements and Reporting**

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

	Yes	No
1 Accounting method used to prepare the Form 990: <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		

- 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).

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

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	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)202-3811** 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.

- I request an additional 3-month extension of time until **NOVEMBER 15, 2013**.
- For calendar year **2012**, or other tax year beginning \_\_\_\_\_, and ending \_\_\_\_\_.
- If the tax year entered in line 5 is for less than 12 months, check reason:  Initial return  Final return  
 Change in accounting period
- State in detail why you need the extension  
**ADDITIONAL TIME I SNEEDED TO GATHER SUFFICIENT INFORMATION IN ORDER TO FILE A COMPLETE INFORMATIONAL RETURN.**

8a If this application is for Form 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.	<b>8a</b>	\$	0.
8b If this application is for Form 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.	<b>8b</b>	\$	0.
8c <b>Balance due.</b> Subtract line 8b from line 8a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.	<b>8c</b>	\$	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

**SCHEDULE A**  
(Form 990 or 990-EZ)

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

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

OMB No. 1545-0047

**2012**

Open to Public Inspection

Name of the organization **HYDROCEPHALIS ASSOCIATION** Employer identification number **94-3000301**

**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? _____	11g(i)	
(ii) A family member of a person described in (i) above? _____	11g(ii)	
(iii) A 35% controlled entity of a person described in (i) or (ii) above? _____	11g(iii)	
- 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	
<b>Total</b>									

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

Schedule A (Form 990 or 990-EZ) 2012

**Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)**

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	1,220,164.	1,701,538.	1,786,923.	1,689,904.	2,247,530.	8,646,059.
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 .....	1,220,164.	1,701,538.	1,786,923.	1,689,904.	2,247,530.	8,646,059.
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) .....						1,476,708.
6 Public support. Subtract line 5 from line 4.						7,169,351.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4 .....	1,220,164.	1,701,538.	1,786,923.	1,689,904.	2,247,530.	8,646,059.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources .....	11,068.	7,012.	17,679.	11,892.	13,640.	61,291.
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.	16,645.
11 Total support. Add lines 7 through 10 .....						8,723,995.
12 Gross receipts from related activities, etc. (see instructions) .....					12	270,383.
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 2012 (line 6, column (f) divided by line 11, column (f)) .....	14	82.18 %
15 Public support percentage from 2011 Schedule A, Part II, line 14 .....	15	81.56 %
16a 33 1/3% support test - 2012. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization .....	<input checked="" type="checkbox"/>	
b 33 1/3% support test - 2011. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization .....	<input type="checkbox"/>	
17a 10% -facts-and-circumstances test - 2012. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....	<input type="checkbox"/>	
b 10% -facts-and-circumstances test - 2011. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....	<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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....						
<b>2</b> 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 .....						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 .....						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>6 Total.</b> Add lines 1 through 5 .....						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons .....						
<b>b</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 .....						
<b>c</b> Add lines 7a and 7b .....						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
<b>9</b> Amounts from line 6 .....						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources .....						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....						
<b>c</b> Add lines 10a and 10b .....						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on .....						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) .....						
<b>13 Total support.</b> (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**

<b>15</b> Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f)) .....	15	%
<b>16</b> Public support percentage from 2011 Schedule A, Part III, line 15 .....	16	%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f)) .....	17	%
<b>18</b> Investment income percentage from 2011 Schedule A, Part III, line 17 .....	18	%

**19a 33 1/3% support tests - 2012.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

**b 33 1/3% support tests - 2011.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

**20 Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions



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

SCHEDULE A, PART II, LINE 10, EXPLANATION FOR OTHER INCOME:

MISCELLANEOUS RECEIPTS

2009 AMOUNT: \$ 2,773.

2010 AMOUNT: \$ 4,780.

2011 AMOUNT: \$ 3,864.

2012 AMOUNT: \$ 5,949.

DISPOSAL OF FIXED ASSETS

2011 AMOUNT: \$ -639.

2012 AMOUNT: \$ -82.

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

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	80,818.	80,718.	80,218.	80,218.	77,648.
b Contributions	300.	100.	500.	0.	2,570.
c Net investment earnings, gains, and losses	4,731.	1,386.	3,895.	1,071.	1,595.
d Grants or scholarships	4,731.	1,386.	3,895.	1,071.	1,595.
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	81,118.	80,818.	80,718.	80,218.	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  .00 %
- b Permanent endowment  100.00 %
- c Temporarily restricted endowment  .00 %

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?		

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

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		78,523.	25,906.	52,617.
e Other				0.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				52,617.

**Part VII Investments - Other Securities.** 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) .....		
(I) .....		
<b>Total.</b> (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ▶		

**Part VIII Investments - Program Related.** See Form 990, Part X, line 13.

(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) .....		
(2) .....		
(3) .....		
(4) .....		
(5) .....		
(6) .....		
(7) .....		
(8) .....		
(9) .....		
(10) .....		
<b>Total.</b> (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ▶		

**Part IX Other Assets.** See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1) .....	
(2) .....	
(3) .....	
(4) .....	
(5) .....	
(6) .....	
(7) .....	
(8) .....	
(9) .....	
(10) .....	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	

**Part X Other Liabilities.** See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) LEASE PAYABLE	16,842.
(3) PAYABLE TO SPONSORED GROUPS	78,088.
(4) .....	
(5) .....	
(6) .....	
(7) .....	
(8) .....	
(9) .....	
(10) .....	
(11) .....	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	94,930.

2. FIN 48 (ASC 740) Footnote. 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**

1	Total revenue, gains, and other support per audited financial statements		1	2,228,525.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains on investments	2a	9,689.	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	9,689.
3	Subtract line 2e from line 1		3	2,218,836.
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	-4,965.	
c	Add lines 4a and 4b		4c	-4,965.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	2,213,871.

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

1	Total expenses and losses per audited financial statements		1	1,843,469.
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	1,843,469.
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	-4,967.	
c	Add lines 4a and 4b		4c	-4,967.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		5	1,838,502.

**Part XIII Supplemental Information**

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

**PART V, LINE 4: THE ORGANIZATION USES ENDOWMENT FUNDS FOR EDUCATIONAL**

**SCHOLARSHIPS TO YOUNG ADULTS WITH HYDROCEPHALUS.**

**PART XI, LINE 4B - OTHER ADJUSTMENTS:**

**COST OF GOODS SOLD INCLUDED IN EXPENSES PER GAAP - (4,965)**

**PART XII, LINE 4B - OTHER ADJUSTMENTS:**

**COST OF GOODS SOLD INCLUDED IN EXPENSES PER GAAP - (4,965)**



**SCHEDULE F  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Statement of Activities Outside the United States**

▶ Complete if the organization answered "Yes" to Form 990,  
Part IV, line 14b, 15, or 16.  
▶ Attach to Form 990. ▶ See separate instructions.

OMB No. 1545-0047

**2012**

Open to Public  
Inspection

Name of the organization

Employer identification number

**HYDROCEPHALIS ASSOCIATION**

**94-3000301**

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

1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? .....  Yes  No

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

3 Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
NORTH AMERICA	0	0	GRANTS TO RECIPIENTS		40,000.
<b>3 a</b> Sub-total .....	0	0			40,000.
<b>b</b> Total from continuation sheets to Part I .....	0	0			0.
<b>c</b> Totals (add lines 3a and 3b) .....	0	0			40,000.

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

Schedule F (Form 990) 2012

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			NORTH AMERICA	FOR THE ESTABLISHED INVESTIGATOR GRANT TO INCREASE KNOWLEDGE ON CEREBAL SPINAL FLUID	40,000.	CHECK	0.		

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

3 Enter total number of other organizations or entities

**HYDROCEPHALIS ASSOCIATION**

94-3000301

**Part III Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

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



**Part IV Foreign Forms**

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* .....  Yes  No
  
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)* .....  Yes  No
  
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations. (see Instructions for Form 5471)* .....  Yes  No
  
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)* .....  Yes  No
  
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect To Certain Foreign Partnerships. (see Instructions for Form 8865)* .....  Yes  No
  
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report. (see Instructions for Form 5713)* .....  Yes  No

**Part V** Supplemental Information

Complete this part to provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information.

SCHEDULE F, PART I, LINE 2: GRANTEES PROVIDE PROGRESS REPORTS AND THESE ARE MONITORED AGAINST APPROVED RESEARCH OBJECTIVES. THESE ARE THEN REVIEWED BY SENIOR HA STAFF AND MEMBERS OF THE RESEARCH COMMITTEE.

PART II, COLUMN (D):

REGION: NORTH AMERICA

(D) PURPOSE OF GRANT: FOR THE ESTABLISHED INVESTIGATOR GRANT TO INCREASE KNOWLEDGE ON CEREBAL SPINAL FLUID REGULATION

**SCHEDULE G**  
(Form 990 or 990-EZ)

Department of the Treasury  
Internal Revenue Service

**Supplemental Information Regarding  
Fundraising or Gaming Activities**

Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19,  
or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.  
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No. 1545-0047

**2012**

**Open To Public  
Inspection**

Name of the organization **HYDROCEPHALIS ASSOCIATION** Employer identification number **94-3000301**

**Part I Fundraising Activities.** Complete if the organization answered "Yes" to Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- a  Mail solicitations
  - b  Internet and email solicitations
  - c  Phone solicitations
  - d  In-person solicitations
  - e  Solicitation of non-government grants
  - f  Solicitation of government grants
  - g  Special fundraising events
- 2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  Yes  No
- b If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
CATHERIN M. CONNOLLY - 3239 PORT PACIFIC LANE, ELK GROVE,	FUNDRAISING		X	132,987.	31,200.	101,787.
<b>Total</b>				132,987.	31,200.	101,787.

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.  
**CA, FL, NC, SC**

**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	
	WALK-A-THON (LI)	WALK-A-THON (CHICAGO)	31	(add col. (a) through col. (c))	
	(event type)	(event type)	(total number)		
<b>Revenue</b>					
1	Gross receipts	77,000.	68,300.	909,612.	1,054,912.
2	Less: Contributions	77,000.	68,300.	909,612.	1,054,912.
3	Gross income (line 1 minus line 2)				
<b>Direct Expenses</b>					
4	Cash prizes				
5	Noncash prizes	5,210.	3,800.	48,650.	57,660.
6	Rent/facility costs	1,750.	5,500.	18,290.	25,540.
7	Food and beverages	650.	570.	12,480.	13,700.
8	Entertainment	450.	1,180.	13,740.	15,370.
9	Other direct expenses	3,900.	4,370.	18,363.	26,633.
10	Direct expense summary. Add lines 4 through 9 in column (d)				( 138,903 )
11	Net income summary. Combine line 3, column (d), and line 10				-138,903.

**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))	
<b>Revenue</b>					
1	Gross revenue				
<b>Direct Expenses</b>					
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. Combine line 1, column d, and line 7				

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:

<b>a</b> The organization's facility	<b>13a</b>	%
<b>b</b> An outside facility	<b>13b</b>	%

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

**SCHEDULE G, PART I, LINE 2B, LIST OF TEN HIGHEST PAID FUNDRAISERS:**

(I) NAME OF FUNDRAISER: CATHERIN M. CONNOLLY

(I) ADDRESS OF FUNDRAISER: 3239 PORT PACIFIC LANE, ELK GROVE, CA 95758

**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

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

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

OMB No. 1545-0047

**2012**

Open to Public  
Inspection

Name of the organization

**HYDROCEPHALIS 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?  Yes  No

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

**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

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
SEATTLE CHILDREN'S HOSPITAL P.O. BOX 50020 MS S200 SEATTLE, WA 98145	91-0564748	501(C)(3)	34,957.	0.			TO SUPPORT THE SEATTLE CHILDREN'S HOSPITAL WORK WITH THE HYDROCEPHALUS CLINICAL RESEARCH NETWORK
PRIMARY CHILDREN'S MEDICAL CENTER 100 MARIO CAPPECHI DRIVE SALT LAKE CITY, UT 84113	87-0453633	501(C)(3)	11,594.	0.			TO FUND HYDROCEPHALUS RESEARCH CONDUCTED AT THE LOCAL HYDROCEPHALUS CLINICAL RESEARCH NETWORK

**2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ..... **2**

**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**

Schedule I (Form 990) (2012)

**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	14	14,000.	0.		

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

SCHEDULE I, PART I, LINE 2: 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: PRIMARY CHILDREN'S MEDICAL CENTER

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

**SCHEDULE J  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Compensation Information**

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

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

▶ Attach to Form 990. ▶ See separate instructions.

OMB No. 1545-0047

**2012**

Open to Public Inspection

Name of the organization

**HYDROCEPHALIS ASSOCIATION**

Employer identification number

**94-3000301**

**Part I Questions Regarding Compensation**

**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.

- |  |  |
|--|--|
| <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

**2** Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all officers, directors, trustees, and the CEO/Executive Director, regarding the items checked in line 1a?

**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.

- |   |   |
|---|---|
| <input checked="" 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**
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan? **4b**
- c** Participate in, or receive payment from, an equity-based compensation arrangement? **4c**
- 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**
- b** Any related organization? **5b**
- 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**
- b** Any related organization? **6b**
- 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

**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

**9** If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

	Yes	No
<b>1b</b>		
<b>2</b>		
<b>4a</b>		X
<b>4b</b>		X
<b>4c</b>		X
<b>5a</b>		X
<b>5b</b>		X
<b>6a</b>		X
<b>6b</b>		X
<b>7</b>		X
<b>8</b>		X
<b>9</b>		





**SCHEDULE L**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Transactions With Interested Persons**

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c, or Form 990-EZ, Part V, line 38a or 40b.**  
▶ **Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.**

OMB No. 1545-0047

**2012**

**Open To Public Inspection**

Name of the organization **HYDROCEPHALIS ASSOCIATION** Employer identification number **94-3000301**

**Part I Excess Benefit Transactions** (section 501(c)(3) and section 501(c)(4) organizations only).  
Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b.

1 (a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
			Yes	No

2 Enter the amount of tax incurred by the organization managers or disqualified persons during the year under section 4958 ..... ▶ \$ \_\_\_\_\_

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ..... ▶ \$ \_\_\_\_\_

**Part II Loans to and/or From Interested Persons.**

Complete if the organization answered "Yes" on Form 990-EZ, Part V, line 38a or Form 990, Part IV, line 26; or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22.

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?		(i) Written agreement?	
			To	From			Yes	No	Yes	No	Yes	No
<b>Total</b> .....						▶ \$						

**Part III Grants or Assistance Benefiting Interested Persons.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance

**Part IV Business Transactions Involving Interested Persons.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
RAS MANAGEMENT	OWNED BY RICK SMITH	51,015.	MANAGEMENT		X

**Part V Supplemental Information**

Complete this part to provide additional information for responses to questions on Schedule L (see instructions).

SCH L, PART IV, BUSINESS TRANSACTIONS INVOLVING INTERESTED PERSONS:

(A) NAME OF PERSON: RAS MANAGEMENT

(B) RELATIONSHIP BETWEEN INTERESTED PERSON AND ORGANIZATION:

OWNED BY RICK SMITH, THE SECRETARY OF THE BOARD

(D) DESCRIPTION OF TRANSACTION: MANAGEMENT SERVICES

**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2012**

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.

Name of the organization **HYDROCEPHALIS 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	5	134,878.	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 ▶ ( VARIOUS ITEMS ) .....	X	2	1,001.	COST
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) (2012)

**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.

OMB No. 1545-0047

**2012**

Open to Public  
Inspection

Name of the organization

HYDROCEPHALIS ASSOCIATION

Employer identification number  
94-3000301

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

INNOVATIVE RESEARCH AND PROVIDING SUPPORT AND EDUCATION FOR  
INDIVIDUALS, FAMILIES AND PROFESSIONALS.

FORM 990, PART III, LINE 2, NEW PROGRAM SERVICES:

RESEARCH CONFERENCE

THE "OPPORTUNITIES FOR HYDROCEPHALUS RESEARCH CONFERENCE" HELD IN  
SEATTLE, WASHINGTON ON JULY 9TH-11TH WAS ATTENDED BY 120 NEUROSURGEONS,  
SCIENTISTS/RESEARCHERS, NEUROLOGISTS, BIOMECHANICAL ENGINEERS,  
NEUROPSYCHOLOGISTS, AND PATIENT ADVOCATES. THIS CONFERENCE WAS  
GROUND-BREAKING IN THAT IT BROUGHT TOGETHER, FOR THE FIRST TIME,  
RESERACHERS AND OTHER INNOVATORS FROM A VARIETY OF BACKGROUNDS TO  
ADDRESS THE STATE OF RESEARCH ON HYDROCEPHALUS AND TO IDENTIFY WHERE  
THE MOST PROMISING RESERACH STILL NEEDS TO BE CONDUCTED. A FINAL REPORT  
FROM THE CONFERENCE IS SCHEDULED FOR PUBLICATION IN AN UPCOMING ISSUE  
OF THE JOURNAL OF NERUOSURGERY - PEDIATRICS. IN ADDITION TO DRIVING AN  
AGENDA FOR FUTURE RESEARCH, THE CONFERENCE PROMOTED COLLABORATION AMONG  
RESERACHERS AND ENCOURAGED RESEARCHERS TO FOCUS ON THE NEED FOR MORE  
STUDY OF HYDROCEPHALUS.

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

COMPLEMENT OF PRINT AND DIGITAL EDUCATIONAL AND RESOURCE MATERIALS FOR  
PATIENTS, FAMILIES, AND MEDICAL PRACTITIONERS.

HA'S TEENS TAKE CHARGE (TTC) PROGRAM WAS FULLY OPERATIONALIZED TO  
MOTIVATE AND EMPOWER YOUNG PEOPLE AFFECTED BY HYDROCEPHALUS TO

Name of the organization HYDROCEPHALIS ASSOCIATION	Employer identification number 94-3000301
---	--

ADVOCATE, RAISE AWARENESS, AND ENCOURAGE PEERS. IN 2012, TTC CONNECTED MORE THAN 800 TEENS THROUGH SOCIAL MEDIA, AND AWARDED FIVE SCHOLARSHIPS TO DESERVING TEENS AND YOUNG ADULTS AFFECTED BY HYDROCEPHALUS. HA ALSO MOBILIZED 10,000 INDIVIDUALS TO PARTICIPATE IN AWARENESS-BUILDING WALKS IN 32 CITIES AROUND THE COUNTRY.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:  
NEEDS NOW AND INTO THE FUTURE.

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

THE ASSOCIATION ALSO RAN A TRAIL-BLAZING RESEARCH CONFERENCE THAT FOR THE FIRST TIME BROUGHT TOGETHER RESEARCHERS, SCIENTISTS AND INNOVATORS FROM A WIDE VARIETY OF DISCIPLINES TO SHARE THE WORK THEY ARE DOING IN THE FIELD OF HYDROCEPHALUS RESEARCH AND TO IDENTIFY WHERE THE BEST OPPORTUNITIES EXIST FOR BREAKTHROUGHS WITH FUTURE STUDY.

THE ASSOCIATION ANNOUNCED A UNIQUE PARTNERSHIP WITH THE RUDI SCHULTE RESEARCH INSTITUTE (RSRI) THAT RESULTED IN A NEW ROUND OF GRANT MONIES BEING MADE AVAILABLE FOR HYDROCEPHALUS RESEARCH.

HA SIGNED A MEMORANDUM OF UNDERSTANDING (MOU) WITH THE HYDROCEPHALUS CLINICAL RESEARCH NETWORK (HCRN), COMMITTING THE ASSOCIATION'S RESOURCES TO FINANCIALLY SUPPORTING THE RESEARCH WORK BEING DONE AT HCRN CENTERS, AND ANNOUNCING THAT A \$500,000 DONATION HAD BEEN RECEIVED TO HELP KICK-OFF THE PARTNERSHIP.

THE ASSOCIATION ALSO SPENT CONSIDERABLE TIME AND RESOURCES IN 2012 TO

Name of the organization

HYDROCEPHALIS ASSOCIATION

Employer identification number

94-3000301

ESTABLISHING AN ADULT HYDROCEPHALUS-FOCUSED NETWORK OF RESEARCHERS WHO, FOLLOWING THE HCRN MODEL, WILL SHARE PATIENT DATA AND WILL COLLABORATE ON STUDIES FOCUSED ON THE CLINICAL TREATMENT OF HYDROCEPHALUS IN ADULTS, INCLUDING NORMAL PRESSURE HYDROCEPHALUS.

IN 2012, ASHLY WESTRICK, MPH, WAS HIRED TO SERVE AS HA'S RESEARCH PROGRAMS MANAGER. SHE REGULARLY ATTENDED SCIENTIFIC MEETINGS WHERE RESEARCHERS PARTICIPATED IN DISCUSSIONS ABOUT NEUROLOGICAL CONDITIONS SUCH AS HYDROCEPHALUS, AND IS A FREQUENT CONTRIBUTOR TO HA'S NEWSLETTERS AND BLOGS WITH INFORMATION ABOUT THE LATEST RESEARCH FINDINGS.

FINALLY, HA BOARD MEMBERS PAUL GROSS AND JOHN KESTLE, MD, UNDERTOOK A PUBLIC RESEARCH LANDSCAPE PROJECT TO IDENTIFY AND CALCULATE THE DOLLAR VOLUME OF PUBLIC FUNDING BEING DEDICATED TO HYDROCEPHALUS RESEARCH. THE RESULTS OF THIS PROJECT WERE COMPILED INTO A SPECIAL REPORT THAT WILL BE PUBLISHED IN A PEER-REVIEWED JOURNAL IN THE NEAR FUTURE.

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

ADVOCACY

THE ASSOCIATION'S ADVOCACY WORK FOCUSED ON EFFORTS TO EDUCATE AND BUILD AWARENESS AMONG PUBLIC POLICY MAKERS AT THE LOCAL, STATE AND NATIONAL LEVELS. LOCALLY, THE HYDROCEPHALUS ASSOCIATION (HA) STRIVES TO BUILD AWARENESS WITH ACTIVITIES SUCH AS OUR HYDROCEPHALUS WALKS, HELD IN 32 CITIES ACROSS THE COUNTRY, WHICH MOBILIZED OVER 10,000 PARTICIPANTS IN 2012. HA ALSO SUPPORTED STATE-LEVEL EFFORTS TO ESTABLISH HYDROCEPHALUS AWARENESS DAYS/MONTHS.

Name of the organization HYDROCEPHALIS ASSOCIATION	Employer identification number 94-3000301
---	--

AT THE FEDERAL LEVEL, THE ASSOCIATION FOCUSED ON EFFORTS TO EDUCATE PUBLIC POLICY MAKERS ON THE CHALLENGES OF LIVING WITH HYDROCEPHALUS AND THE NEED FOR EXPANDED RESEARCH. TO DO THIS, HA PRESENTED 3 PUBLIC SERVICE AWARDS TO MEMBERS OF CONGRESS FOR THEIR SUPPORT OF THOSE AFFLICTED BY HYDROCEPHALUS; CONDUCTED AN INTENSIVE TRAINING PROGRAM AND ISSUES BRIEFING FOR THOSE INTERESTED IN PARTICIPATING IN GRASSROOTS CAMPAIGNS; HELD AN ADVOCACY DAY WHERE OVER 200 PATIENTS AND THEIR CAREGIVERS VISITED WITH LEGISLATORS AND THEIR STAFFS TO SHARE THEIR UNIQUE PERSPECTIVES ABOUT THE ROLE OF PUBLIC FUNDING FOR RESEARCH. HA ALSO PLAYS AN ACTIVE ROLE IN A SERIES OF PATIENT ADVOCACY COALITIONS TO FIND COMMONLY-SUPPORTABLE SOLUTIONS TO PUBLIC POLICY QUESTIONS AFFECTING PATIENTS AND THEIR FAMILIES. AS A RESULT OF THE ASSOCIATION'S WORK IN 2012, THE NIH HAS AGREED TO INCLUDE HYDROCEPHALUS AS A NEW RESEARCH CATEGORY IN ITS RESEARCH, CONDITION, AND DISEASE CATEGORIZATION REPORTS, RESULTING IN A NEW LEVEL OF TRANSPARENCY AROUND THE AMOUNT OF FEDERAL DOLLARS SPENT ON HYDROCEPHALUS RESEARCH STARTING IN 2013.

EXPENSES \$ 104,959. INCLUDING GRANTS OF \$ 5,325. REVENUE \$ 779.

#### RESEARCH CONFERENCE

THE "OPPORTUNITIES FOR HYDROCEPHALUS RESEARCH CONFERENCE" HELD IN SEATTLE, WASHINGTON ON JULY 9TH-11TH WAS ATTENDED BY 120 NEUROSURGEONS, SCIENTISTS/RESEARCHERS, NEUROLOGISTS, BIOMECHANICAL ENGINEERS, NEUROPSYCHOLOGISTS, AND PATIENT ADVOCATES. THIS CONFERENCE WAS GROUND-BREAKING IN THAT IT BROUGHT TOGETHER, FOR THE FIRST TIME, RESERACHERS AND OTHER INNOVATORS FROM A VARIETY OF BACKGROUNDS TO ADDRESS THE STATE OF RESEARCH ON HYDROCEPHALUS AND TO IDENTIFY WHERE THE MOST PROMISING RESERACH STILL NEEDS TO BE CONDUCTED. A FINAL REPORT



Name of the organization HYDROCEPHALIS ASSOCIATION	Employer identification number 94-3000301
---	--

FROM THE CONFERENCE IS SCHEDULED FOR PUBLICATION IN AN UPCOMING ISSUE OF THE JOURNAL OF NERUOSURGERY - PEDIATRICS. IN ADDITION TO DRIVING AN AGENDA FOR FUTURE RESEARCH, THE CONFERENCE PROMOTED COLLABORATION AMONG RESERACHERS AND ENCOURAGED RESEARCHERS TO FOCUS ON THE NEED FOR MORE STUDY OF HYDROCEPHALUS.

EXPENSES \$ 104,299. INCLUDING GRANTS OF \$ 0. REVENUE \$ 17,536.

FORM 990, PART VI, SECTION A, LINE 1: 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 BAORD. THE EXECUTIVE COMMITTEE IS COMPOSED OF 1) PAUL GROSS, CHAIRMAN; 2) RAY MOSER, SENIOR VICE CHAIRMAN; 3) BARRETT O'CONNOR, CHAIRWOMAN; 4) RICK SMITH, SECRETARY; 5) CRAIG BROWN, TREASURER. EVERY EXECUTIVE COMMITTEE IS ON THE GOVERNING BOARD.

FORM 990, PART VI, SECTION A, LINE 3: RICK SMITH OWNS RAS MANAGEMENT SERVICES, WHICH WAS CONTRACTED BY THE HYDROCEPHALUS ASSOCIATION TO PROVIDE INTERIM CEO SERVICES. FROM JANUARY 2011-JANUARY 2012, RICK SMITH SERVED AS INTERIM CEO.

FORM 990, PART VI, SECTION A, LINE 4: ADDED CEO AS EX-OFFICIO, NON-VOTING MEMBER OF THE BOARD OF DIRECTORS.

ADDED CEO AS EX-OFFICIO, NON-VOTING MEMBER OF THE CORPORATION AND AS AN EX-OFFICIO, NON-VOTING MEMBER OF THE EXECUTIVE COMMITTEE.

FORM 990, PART VI, SECTION A, LINE 5: AN EMPLOYEE USED COMPANY CREDIT AND DEBIT CARDS AND FUNDS FROM THE ASSOCIATION'S OPERATING ACCOUNT TO PAY FOR

Name of the organization

HYDROCEPHALIS ASSOCIATION

Employer identification number

94-3000301

APPROXIMATELY \$30,000 OF IMPROPER AND NON-AUTHORIZED PERSONAL EXPENDITURES. THE ASSOCIATION HAS DOCUMENTED THE LOSS AND ENGAGED LEGAL COUNSEL ON A PRO BONO BASIS TO FILE A COMPLAINT AND SECURE JUDGEMENT AGAINST SAID EMPLOYEE (NOW FORMER EMPLOYEE) WITH THE SUPERIOR COURT OF THE STATE OF CALIFORNIA.

FORM 990, PART VI, SECTION B, LINE 11: ALL BOARD MEMBERS WILL RECEIVE A COPY OF THE TAX RETURN AFTER ITS FILING.

FORM 990, PART VI, SECTION B, LINE 12C: EACH YEAR BOARD MEMBERS GETS A COPY OF THE CONFLICT OF INTEREST POLICY AND A DISCLOSURE FORM WHICH IS FILLED OUT IF ANY POSSIBLE CONFLICTS MAY EXIST.

FORM 990, PART VI, SECTION B, LINE 15A: THE PROCESS FOR DETERMINING THE CHIEF EXECUTIVE OFFICER'S (WHO IS ALSO IN CHARGE OF FINANCIAL MANAGEMENT OF THE ORGANIZATION) SALARY INCLUDES THE FOLLOWING STEPS:

1) BOARD CHAIRMAN AND CHIEF EXECUTIVE OFFICER EACH COLLECT COMPARABLE SALARY INFORMATION (E.G., SALARY STUDIES)

2) THE INFORMATION IS FORWARDED TO THE TREASURER WHO DOCUMENTS FINDINGS FROM DATA COLLECTED

3) TREASURER MAKES A RECOMMENDATION TO THE FULL BOARD

4) THE BOARD VOTES ON THE PROPOSED SALARY

OTHER SALARIES OF SENIOR MANAGERS ARE BENCHMARKED USING CURRENT SALARY SURVEY DATA; OUR GOAL IS TO PROVIDE THE MEDIAN SALARY PROVIDED BY SIMILAR ORGANIZATIONS.

FORM 990, PART VI, SECTION C, LINE 19: THE ORGANIZATION'S GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS ARE AVAILABLE TO THE PUBLIC AT THE ORGANIZATION'S OFFICE UPON REQUEST.