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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)

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

OMB No 1545-0047

2009

Open to Public Inspection

A For the **2009** calendar year, or tax year beginning **APR 1, 2009** and ending **MAR 31, 2010**

B Check if applicable: ☐ Address change ☐ Name change ☐ Initial return ☐ Terminated ☐ Amended return ☐ Application pending	Please use IRS label or print or type See Specific Instructions	C Name of organization NATIONAL DOWN SYNDROME SOCIETY Doing Business As Number and street (or P.O. box if mail is not delivered to street address) Room/suite 666 BROADWAY City or town, state or country, and ZIP + 4 NEW YORK, NY 10012 F Name and address of principal officer: JONATHAN COLMAN SAME AS C ABOVE	D Employer identification number 13-2992567 E Telephone number (212) 460-9330 G Gross receipts \$ 4,714,737. 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) (insert no.) ☐ 4947(a)(1) or ☐ 527		J Website: ▶ WWW.NDSS.ORG	
K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶		L Year of formation: 1979 M State of legal domicile: DE	

Part I Summary			
Activities & Governance	1 Briefly describe the organization's mission or most significant activities: TO BE THE NATIONAL ADVOCATE FOR THE VALUE, ACCEPTANCE AND INCLUSION OF PEOPLE WITH DOWN SYNDROME 2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets. 3 Number of voting members of the governing body (Part VI, line 1a) 3 19 4 Number of independent voting members of the governing body (Part VI, line 1b) 4 19 5 Total number of employees (Part V, line 2a) 5 15 6 Total number of volunteers (estimate if necessary) 6 101 7a Total gross unrelated business revenue from Part VIII, column (C), line 12 7a 0. b Net unrelated business taxable income from Form 990-T, line 34 7b 0.		
Revenue	8 Contributions and grants (Part VIII, line 1h) 9 Program service revenue (Part VIII, line 2g) 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) 11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	Prior Year	Current Year
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) 14 Benefits paid to or for members (Part IX, column (A), line 4) 15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) 16a Professional fundraising fees (Part IX, column (A), line 11e) b Total fundraising expenses (Part IX, column (D), line 25) ▶ 232,307. 17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24f) 18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) 19 Revenue less expenses. Subtract line 18 from line 12	1,216,095.	1,178,857.
Net Assets or Fund Balances	20 Total assets (Part X, line 16) 21 Total liabilities (Part X, line 26) 22 Net assets or fund balances. Subtract line 21 from line 20	Beginning of Current Year	End of Year
		2,672,502.	3,030,114.
		274,290.	189,689.
		2,398,212.	2,840,425.

Part II Signature Block			
Sign Here	Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge. Signature of officer: JONATHAN COLMAN, PRESIDENT Type or print name and title	Date	11/4/10
Paid Preparer's Use Only	Preparer's signature: Firm's name (or yours if self-employed), address, and ZIP + 4: WEISER LLP 135 W 50TH STREET NEW YORK, NY 10020	Date: 11/3/10 Check if self-employed: ☐	Preparer's identifying number (see instructions): EIN ▶ Phone no. ▶ 212-812-7000

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

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Part III Statement of Program Service Accomplishments

1 Briefly describe the organization's mission:

THE MISSION OF THE NATIONAL DOWN SYNDROME SOCIETY IS TO BE THE NATIONAL ADVOCATE FOR THE VALUE, ACCEPTANCE AND INCLUSION OF PEOPLE WITH DOWN SYNDROME.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?

☐ Yes ☒ No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?

☐ Yes ☒ No

If "Yes," describe these changes on Schedule O.

4 Describe the exempt purpose achievements for each of the organization's three largest program services by expenses.

Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts 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 \$ 401,341. including grants of \$) (Revenue \$ 0.)

BUDDY WALKS - NDSS OWNS AND OPERATES THE NATIONAL BUDDY WALK PROGRAM, OVERSEEING MORE THAN 300 WALK ACROSS THE U.S. AND THROUGHOUT THE COUNTRY. LAST YEAR, 250,000 PEOPLE PARTICIPATED IN A BUDDY WALK! THEY RAISED MORE THAN \$9.5 MILLION TO BENEFIT LOCAL PROGRAMS AND SERVICES AS WELL AS THE NATIONAL ADVOCACY INITIATIVES THAT BENEFIT ALL INDIVIDUALS WITH DOWN SYNDROME. NDSS ALSO HOLDS ITS NATIONAL BUDDY WALK IN NEW YORK CITY, WHICH WAS ATTENDED BY 2,000 PEOPLE.

4b (Code:) (Expenses \$ 397,370. including grants of \$ 5,840.) (Revenue \$ 0.)

COMMUNITY RELATIONS - THROUGH ITS TOLL-FREE HELPLINE AND E-MAIL SERVICES, NDSS RECEIVED THOUSANDS OF REQUESTS FOR INFORMATION ON DOWN SYNDROME. NDSS PUBLISHED NEW AND EXPECTANT PARENT GUIDES AND INFORMATIONAL BROCHURES IN BOTH ENGLISH AND SPANISH. NDSS'S WEBSITE, WHICH PROVIDES A COMPREHENSIVE AND UP-TO-DATE RESOURCE FOR FAMILIES, PROFESSIONALS, AFFILIATES AND OTHERS, RECEIVED OVER 3 MILLION PAGE VIEWS. NDSS CONDUCTED WEBINARS ONCE A MONTH AND OFFERED EDUCATIONAL SEMINARS.

4c (Code:) (Expenses \$ 389,729. including grants of \$) (Revenue \$ 0.)

PUBLIC POLICY- THE NDSS NATIONAL POLICY CENTER STRIVES TO PROTECT THE RIGHTS AND REMOVE THE BARRIERS OF ALL INDIVIDUALS WITH DOWN SYNDROME. THE POLICY CENTER WORKED WITH CONGRESS AND FEDERAL AGENCIES TO DEVELOP AND IMPROVE LAWS, REGULATIONS AND OTHER POLICIES, TRAINED AND EDUCATED PARENTS, SELF-ADVOCATES AND OTHERS TO ADVOCATE ON THE LOCAL, STATE AND NATIONAL LEVELS, ORGANIZED AND PARTICIPATED IN COALITIONS OF NATIONAL DISABILITY ORGANIZATIONS, AND LED NATIONAL AND STATEWIDE GOVERNMENTAL AFFAIRS COMMITTEES. SPECIFICALLY NDSS HELPED TO GET INTRODUCED THE TRISOMY 21 TRANSLATIONAL RESEARCH PARITY ACT.

4d Other program services. (Describe in Schedule O)

(Expenses \$ 346,382. including grants of \$ 54,221.) (Revenue \$)

4e Total program service expenses ▶ \$ 1,534,822.

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>	1 X	
2 Is the organization required to complete Schedule B, Schedule of Contributors?	2 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>	3	X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities? <i>If "Yes," complete Schedule C, Part II</i>	4 X	
5 Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? <i>If "Yes," complete Schedule C, Part III</i>	5	
6 Did the organization maintain any donor advised funds or any similar funds or accounts where 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>	6	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>	7	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>	8	X
9 Did the organization report an amount in Part X, line 21; 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>	9	X
10 Did the organization, directly or through a related organization, hold assets in term, permanent, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>	10 X	
11 Is the organization's answer to any of the following questions "Yes"? <i>If so, complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable</i>	11 X	
• 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>		
• 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>		
• 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>		
• 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>		
• Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		
• 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? <i>If "Yes," complete Schedule D, Part X.</i>		
12 Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI, XII, and XIII.</i>	12 X	
12A Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," completing Schedule D, Parts XI, XII, and XIII is optional</i>	12A Yes No X	
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>	13	X
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the United States? <i>If "Yes," complete Schedule F, Part I</i>	14b	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, Part II</i>	15	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, Part III</i>	16	X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>	17	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>	18 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>	19	X
20 Did the organization operate one or more hospitals? <i>If "Yes," complete Schedule H</i>	20	X

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Part IV Checklist of Required Schedules (continued)

	Yes	No
21 Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21 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>	22 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>	23 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>	24a	X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b	
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c	
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d	
25a Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a	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>	25b	X
26 Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	26	X
27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III</i>	27	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>	28a	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>	28b	X
c An entity of which a current or former officer, director, trustee, or key employee of the organization (or a family member) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c	X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29 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>	30	X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	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>	32	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>	33	X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34	X
35 Is any related organization a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35	X
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36	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>	37	X
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O.	38 X	

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Part V Statements Regarding Other IRS Filings and Tax Compliance

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096, Annual Summary and Transmittal of U.S. Information Returns. Enter -0- if not applicable	25	
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	0	
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	X
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	15	
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file this return. (see instructions)	2b	X
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?	3a	X
b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O	3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a	X
b	If "Yes," enter the name of the foreign country: <u>See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.</u>		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	X
c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T, Disclosure by Tax-Exempt Entity Regarding Prohibited Tax Shelter Transaction?	5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible?	6a	X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	X
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	X
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d	
e	Did the organization, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	X
g	For all contributions of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	For contributions of cars, boats, airplanes, and other vehicles, did the organization file a Form 1098-C as required?	7h	
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8	
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the organization make any taxable distributions under section 4966?	9a	
b	Did the organization make a distribution to a donor, donor advisor, or related person?	9b	
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b	
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	

Form 990 (2009)

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.

Section A. Governing Body and Management

	Yes	No
1a Enter the number of voting members of the governing body	19	
b Enter the number of voting members that are independent	19	
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 organizational documents since the prior Form 990 was filed?		X
5 Did the organization become aware during the year of a material diversion of the organization's assets?		X
6 Does the organization have members or stockholders?		X
7a Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?		X
b Are any decisions of the governing body subject to approval by members, stockholders, or other persons?		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 Does the organization have local chapters, branches, or affiliates?		X
b If "Yes," does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?		
11 Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form?	X	
11A Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
12a Does the organization have a written conflict of interest policy? If "No," go to line 13	X	
b Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
c Does the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this is done	X	
13 Does the organization have a written whistleblower policy?	X	
14 Does 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	
b Other officers or key employees of the organization		X
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
b If "Yes," has the organization adopted a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed **NY, AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS**

18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.
☒ Own website ☐ Another's website ☒ Upon request

19 Describe in Schedule O whether (and if so, how), the organization makes its governing documents, conflict of interest policy, and financial statements available to the public.

20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization: **HARRY JELLINEK - (212) 763-4368**
666 BROADWAY, NEW YORK, NY 10012

Form 990 (2009)

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**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. Use Schedule J-2 if additional space is needed.

• 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. 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 the organization did not compensate any current officer, director, or trustee.

(A) Name and Title	(B) Average hours per week	(C) Position (check all that apply)						(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			
ELIZABETH F. GOODWIN FOUNDER	1.50	X						0.	0.	0.
JO ANN SIMONS CHAIRPERSON	17.50	X		X				0.	0.	0.
ROBERT F. CIOFFI VICE CHAIRPERSON	1.50	X		X				0.	0.	0.
TERRANCE P. CLANCY TREASURER	1.50	X		X				0.	0.	0.
BRIAN SKOTKO, M.D., M.P. SECRETARY	1.50	X		X				0.	0.	0.
JOSEPH A BOCKERSTETTE SENIOR ADVISOR	1.50	X						0.	0.	0.
TIFFANY BARFIELD BOARD MEMBER	0.70	X						0.	0.	0.
DOUGLAS BIKLEN BOARD MEMBER	0.70	X						0.	0.	0.
STEPHEN BECK, JR BOARD MEMBER	0.70	X						0.	0.	0.
CHRISTOPHER J. GEDNEY BOARD MEMBER	0.70	X						0.	0.	0.
CHARLES H. GERHARDT, III BOARD MEMBER	0.70	X						0.	0.	0.
JOHN DAVID HOPPE BOARD MEMBER	0.70	X						0.	0.	0.
THOMAS HEHIR BOARD MEMBER	0.70	X						0.	0.	0.
IRA T. LOTT, M.D. BOARD MEMBER	0.70	X						0.	0.	0.
DAVID PATTERSON, PH.D. BOARD MEMBER	0.70	X						0.	0.	0.
CAPT. ROBERT P. TAISHOFF BOARD MEMBER	0.70	X						0.	0.	0.
SARA C. WOLFF BOARD MEMBER	0.70	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	(C) Position (check all that apply)						(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			
JIM NUSSLE BOARD MEMBER	0.70	X						0.	0.	0.
ERIN THOMPSON BOARD MEMBER	0.70	X						0.	0.	0.
JONATHAN COLMAN PRESIDENT	40.00			X				158,545.	0.	8,629.
HARRY JELLINEK DIRECTOR OF FINANCE	40.00			X				92,756.	0.	14,721.
SARAH SCHLEIDER V.P. MARKETING AND COMMU	40.00					X		111,363.	0.	4,712.
MADELEINE WILL DIRECTOR, NATIONAL POLIC	40.00					X		112,111.	0.	4,948.
PAMELA SANDONATO VP DEVELOPMENT	40.00					X		102,919.	0.	605.
1b Total								577,694.	0.	33,615.

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 in reportable compensation from the organization **4**

- 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
- 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
- 5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization for services rendered to the organization? If "Yes," complete Schedule J for such person

	Yes	No
3		X
4	X	
5		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. **NONE**

(A) Name and business address	(B) Description of services	(C) Compensation

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

Part VIII Statement of Revenue

				(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	133,418.				
	b Membership dues	1b					
	c Fundraising events	1c	748,614.				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	1108101.				
	g Noncash contributions included in lines 1a-1f \$		123,896.				
	h Total. Add lines 1a-1f			1990133.			
Program Service Revenue	2 a EDUCATIONAL MATERIALS	Business Code	453000	10,614.	10,614.		
	b CONFERENCE FEES		611710	7,650.	7,650.		
	c CONSULTANT FEES		541610	2,000.	2,000.		
	d						
	e						
	f All other program service revenue						
	g Total. Add lines 2a-2f			20,264.			
	Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			49,246.		
4 Income from investment of tax-exempt bond proceeds							
5 Royalties				301.			301.
6 a Gross Rents		(i) Real	84,430.				
b Less: rental expenses		(ii) Personal	18,294.				
c Rental income or (loss)			66,136.				
d Net rental income or (loss)				66,136.			66,136.
7 a Gross amount from sales of assets other than inventory		(i) Securities	2,290,456.				
b Less: cost or other basis and sales expenses		(ii) Other	2,241,919.				
c Gain or (loss)			48,537.				
d Net gain or (loss)				48,537.			48,537.
8 a Gross income from fundraising events (not including \$ 748,614. of contributions reported on line 1c). See Part IV, line 18							
b Less: direct expenses		a	276471.				
c Net income or (loss) from fundraising events		b	323287.				
9 a Gross income from gaming activities. See Part IV, line 19							
b Less: direct expenses	a						
c Net income or (loss) from gaming activities	b						
10 a Gross sales of inventory, less returns and allowances							
b Less: cost of goods sold	a						
c Net income or (loss) from sales of inventory	b						
Miscellaneous Revenue			Business Code				
11 a MISCELLANEOUS		900099	3,436.			3,436.	
b							
c							
d All other revenue							
e Total. Add lines 11a-11d			3,436.				
12 Total revenue. See instructions.				2131237.	20,264.	0.	120,840.

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) but are not required to complete columns (B), (C), and (D).

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 U.S. See Part IV, line 21	54,221.	54,221.		
2 Grants and other assistance to individuals in the U.S. See Part IV, line 22	5,840.	5,840.		
3 Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	162,234.	103,830.	34,069.	24,335.
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	866,144.	684,194.	94,633.	87,317.
8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)	23,807.	18,255.	2,971.	2,581.
9 Other employee benefits	43,817.	35,311.	3,903.	4,603.
10 Payroll taxes	82,855.	63,740.	10,127.	8,988.
11 Fees for services (non-employees):				
a Management				
b Legal	9,957.		9,957.	
c Accounting	23,191.		23,191.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	10,646.		10,646.	
g Other	140,042.	132,369.	4,899.	2,774.
12 Advertising and promotion				
13 Office expenses	202,105.	118,910.	23,973.	59,222.
14 Information technology	62,651.	53,129.	4,544.	4,978.
15 Royalties				
16 Occupancy	34,948.	26,490.	2,859.	5,599.
17 Travel	52,429.	48,767.	935.	2,727.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	37,295.	35,262.	2,002.	31.
20 Interest	63.		63.	
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	47,439.	37,524.	4,734.	5,181.
23 Insurance				
24 Other expenses. Itemize expenses not covered above. (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below.)				
a PUBLIC SERVICE ANCMTS.	91,155.	91,155.		
b MISCELLANEOUS	32,702.	25,825.	2,627.	4,250.
c CREDIT CARD FEES	19,721.			19,721.
d				
e				
f All other expenses				
25 Total functional expenses. Add lines 1 through 24f	2,003,262.	1,534,822.	236,133.	232,307.
26 Joint costs. Check here ☐ if following SOP 98-2. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				

Part X Balance Sheet

		(A) Beginning of year		(B) End of year
Assets	1 Cash - non-interest-bearing	191,485.	1	154,914.
	2 Savings and temporary cash investments	770,718.	2	524,515.
	3 Pledges and grants receivable, net	69,291.	3	55,210.
	4 Accounts receivable, net		4	12,443.
	5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B). Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	58,678.	9	74,938.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 822,048.		
	b Less: accumulated depreciation	10b 420,943.		
		399,468.	10c	401,105.
	11 Investments - publicly traded securities	1,177,218.	11	1,805,175.
	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	5,644.	15	1,814.	
16 Total assets. Add lines 1 through 15 (must equal line 34)	2,672,502.	16	3,030,114.	
Liabilities	17 Accounts payable and accrued expenses	210,851.	17	173,536.
	18 Grants payable		18	
	19 Deferred revenue	57,450.	19	7,587.
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability Complete Part IV of Schedule D		21	
	22 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 Complete Part X of Schedule D	5,989.	25	8,566.
	26 Total liabilities. Add lines 17 through 25	274,290.	26	189,689.
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here ☒ and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	1,995,075.	27	2,545,321.
	28 Temporarily restricted net assets	403,137.	28	274,288.
	29 Permanently restricted net assets		29	20,816.
	Organizations that do not follow SFAS 117, check here ☐ and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	2,398,212.	33	2,840,425.
34 Total liabilities and net assets/fund balances	2,672,502.	34	3,030,114.	

Form 990 (2009)

Part XI Financial Statements and Reporting

- 1** Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other _____
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.
- 2a** Were the organization's financial statements compiled or reviewed by an independent accountant?
- b** Were the organization's financial statements audited by an independent accountant?
- 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.
- d** If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a consolidated basis, separate basis, or both:
☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis
- 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?
- 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

	Yes	No
2a		X
2b	X	
2c	X	
3a		X
3b		

Form 990 (2009)

Department of the Treasury
Internal Revenue Service

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

OMB No. 1545-0047

2009

Open to Public Inspection

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number

13-2992567

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 - Other

e ☐ By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).

f ☐ If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box

g ☐ Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

(i) ☐ A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?

(ii) ☐ A family member of a person described in (i) above?

(iii) ☐ A 35% controlled entity of a person described in (i) or (ii) above?

h ☐ Provide the following information about the supported organization(s).

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

[illegible]

Schedule A (Form 990 or 990-EZ) 2009

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

(Complete only if you checked the box on line 5, 7, or 8 of Part I.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	1,565,894.	2,686,202.	2,690,807.	2,062,617.	1,990,133.	10,995,653.
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	1,565,894.	2,686,202.	2,690,807.	2,062,617.	1,990,133.	10,995,653.
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)						227,472.
6 Public support. Subtract line 5 from line 4						10,768,181.

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4	1,565,894.	2,686,202.	2,690,807.	2,062,617.	1,990,133.	10,995,653.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	83,700.	86,474.	133,180.	138,732.	133,977.	576,063.
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.)	1,385.	4,075.	725.	2,579.	3,436.	12,200.
11 Total support. Add lines 7 through 10						11,583,916.
12 Gross receipts from related activities, etc. (see instructions)					12	353,081.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ☐						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2009 (line 6, column (f) divided by line 11, column (f))	14	92.96	%
15 Public support percentage from 2008 Schedule A, Part II, line 14	15	93.59	%
16a 33 1/3% support test - 2009. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ☒			
b 33 1/3% support test - 2008. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ☐			
17a 10% -facts-and-circumstances test - 2009. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ☐			
b 10% -facts-and-circumstances test - 2008. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ☐			
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ☐			

Schedule A (Form 990 or 990-EZ) 2009

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.)**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support (Add lines 9, 10c, 11, and 12)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ☐						

Section C. Computation of Public Support Percentage

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

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2009 (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from 2008 Schedule A, Part III, line 17	18	%
19a 33 1/3% support tests - 2009. 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 - 2008. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization ☐		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ☐		

Schedule A (Form 990 or 990-EZ) 2009

SCHEDULE C
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities
For Organizations Exempt From Income Tax Under section 501(c) and section 527

OMB No 1545-0047

2009

**Open to Public
Inspection**

▶ **Complete if the organization is described below.**

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

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

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

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

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

If the organization answered "Yes," to Form 990, Part IV, line 5 (Proxy Tax), then

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

Name of organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number

13-2992567

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

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

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

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

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

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

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

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

Schedule C (Form 990 or 990-EZ) 2009

LHA

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

- A Check ☐ if the filing organization belongs to an affiliated group.
 B Check ☐ if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)		24,501.													
b Total lobbying expenditures to influence a legislative body (direct lobbying)		45,172.													
c Total lobbying expenditures (add lines 1a and 1b)		69,673.													
d Other exempt purpose expenditures		1,933,589.													
e Total exempt purpose expenditures (add lines 1c and 1d)		2,003,262.													
f Lobbying nontaxable amount. Enter the amount from the following table in both columns.		250,163.													
<table border="1"> <thead> <tr> <th>If the amount on line 1e, column (a) or (b) is:</th> <th>The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e.	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	Over \$17,000,000	\$1,000,000.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e.														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.														
Over \$17,000,000	\$1,000,000.														
g Grassroots nontaxable amount (enter 25% of line 1f)		62,541.													
h Subtract line 1g from line 1a. If zero or less, enter -0-		0.													
i Subtract line 1f from line 1c. If zero or less, enter -0-		0.													
j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?			☐ Yes ☐ No												

4-Year Averaging Period Under Section 501(h)

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

Lobbying Expenditures During 4-Year Averaging Period

Calendar year (or fiscal year beginning in)	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) Total
2a Lobbying nontaxable amount	285,078.	268,629.	265,468.	250,163.	1,069,338.
b Lobbying ceiling amount (150% of line 2a, column (e))					1,604,007.
c Total lobbying expenditures	29,443.	51,187.	41,699.	69,673.	192,002.
d Grassroots nontaxable amount	71,270.	67,157.	66,367.	62,541.	267,335.
e Grassroots ceiling amount (150% of line 2d, column (e))					401,003.
f Grassroots lobbying expenditures	5,084.	26,885.	25,848.	24,501.	82,318.

Schedule C (Form 990 or 990-EZ) 2009

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

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

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

Complete this part to provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; and Part II-B, line 1i. Also, complete this part for any additional information.

Schedule D
(Form 990)Department of the Treasury
Internal Revenue Service**Supplemental Financial Statements**

▶ Complete if the organization answered "Yes," to Form 990,

Part IV, line 6, 7, 8, 9, 10, 11, or 12.

▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

2009Open to Public
Inspection

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number

13-2992567

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

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

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

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

☐ Preservation of land for public use (e.g., recreation or pleasure)	☐ Preservation of an historically important land area
☐ Protection of natural habitat	☐ Preservation of a certified historic structure
☐ Preservation of open space	

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

	Held at the End of the Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 8/17/06	2d

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

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

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

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

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

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? ☐ Yes ☐ No

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

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

1a If the organization elected, as permitted under SFAS 116, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items.

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

(i) Revenues included in Form 990, Part VIII, line 1	▶ \$ _____
(ii) Assets included in Form 990, Part X	▶ \$ _____

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

a Revenues included in Form 990, Part VIII, line 1	▶ \$ _____
b Assets included in Form 990, Part X	▶ \$ _____

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

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

(check all that apply):

a ☐ Public exhibitiond ☐ Loan or exchange programsb ☐ Scholarly researche ☐ Other _____c ☐ Preservation for future generations

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

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 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 XIV and complete the following table:

	Amount
1c	
1d	
1e	
1f	

c Beginning balance

d Additions during the year

e Distributions during the year

f 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 XIV.

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					
b Contributions	20,816.				
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	20,816.				

2 Provide the estimated percentage of the year end balance held as:

a Board designated or quasi-endowment ☐ %b Permanent endowment ☒ 100.00 %c Term endowment ☐ %

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

(i) unrelated organizations

(ii) related organizations

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

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

	Yes	No
3a(i)		X
3a(ii)		X
3b		

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

Description of investment	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings		350,796.	180,963.	169,833.
c Leasehold improvements		233,070.	70,350.	162,720.
d Equipment		238,182.	169,630.	68,552.
e Other				
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				401,105.

Schedule D (Form 990) 2009

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
Financial derivatives		
Closely-held equity interests		
Other		
Total. (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
Total. (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
Total. (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) Amount
Federal income taxes	
SECURITY DEPOSIT PAYABLE	8,566.
Total. (Column (b) must equal Form 990, Part X, col (B) line 25.) ►	
	8,566.

2. FIN 48 Footnote. In Part XIV, 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.

Part XI Reconciliation of Change in Net Assets from Form 990 to Audited Financial Statements

1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	2,131,237.
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	2,003,262.
3	Excess or (deficit) for the year. Subtract line 2 from line 1	3	127,975.
4	Net unrealized gains (losses) on investments	4	314,238.
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV.)	8	
9	Total adjustments (net). Add lines 4 through 8	9	314,238.
10	Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9	10	442,213.

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

1	Total revenue, gains, and other support per audited financial statements	1	2,434,829.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains on investments	2a	314,238.
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV.)	2d	
e	Add lines 2a through 2d	2e	314,238.
3	Subtract line 2e from line 1	3	2,120,591.
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	10,646.
b	Other (Describe in Part XIV.)	4b	
c	Add lines 4a and 4b	4c	10,646.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	2,131,237.

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

1	Total expenses and losses per audited financial statements	1	1,992,616.
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 XIV.)	2d	
e	Add lines 2a through 2d	2e	0.
3	Subtract line 2e from line 1	3	1,992,616.
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	10,646.
b	Other (Describe in Part XIV.)	4b	
c	Add lines 4a and 4b	4c	10,646.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)	5	2,003,262.

Part XIV 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, line 8; Part XII, lines 2d and 4b; and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

PART V, LINE 4 - THE ENDOWMENT FUND WILL BE USED FOR SCHOLARSHIPS TO

ATTEND SOME OF NDSS'S ONE-DAY CONFERENCES.

Department of the Treasury
Internal Revenue Service

▶ **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.**

2009

Open To Public Inspection

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number
13-2992567

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 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			
Total						

Total

- 3** List all states in which the organization is registered or licensed to solicit funds or has been notified it is exempt from registration or licensing.

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 on Form 990-EZ, line 6a. List events with gross receipts greater than \$5,000.

	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))
	BUDDY WALKS	ANNUAL GALA	2	
	(event type)	(event type)	(total number)	
Revenue				
1 Gross receipts	241,944.	376,011.	407,130.	1,025,085.
2 Less: Charitable contributions	200,444.	278,731.	269,439.	748,614.
3 Gross income (line 1 minus line 2)	41,500.	97,280.	137,691.	276,471.
Direct Expenses				
4 Cash prizes				
5 Noncash prizes		54,347.	39,983.	94,330.
6 Rent/facility costs	19,547.	14,625.	58,574.	92,746.
7 Food and beverages	6,953.	42,417.	31,743.	81,113.
8 Entertainment	8,200.	1,000.	1,150.	10,350.
9 Other direct expenses	12,900.	1,720.	30,128.	44,748.
10 Direct expense summary. Add lines 4 through 9 in column (d)				323,287.
11 Net income summary. Combine line 3, column (d), and line 10				<46,816.>

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

	(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue				
1 Gross revenue				
Direct Expenses				
2 Cash prizes				
3 Noncash prizes				
4 Rent/facility costs				
5 Other direct expenses				
6 Volunteer labor	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ 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?

b If "No," explain:

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?

b If "Yes," explain:

11 Does the organization operate gaming activities with nonmembers?

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
9a		
10a		
11		
12		

13 Indicate the percentage of gaming activity operated in:**a** The organization's facility**13a** %**b** An outside facility**13b** %**14** Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ► _____

Address ► _____

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue?**15a****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?**17a****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 ► \$ _____

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

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

► **Attach to Form 990.**

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer Identification number
13-2992567

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

De 2

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

Part II

[illegible]

2 Enter total number of section 501(c)(3) and government organizations

3 Enter total number of other organizations

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

SEE PART IV FOR COLUMN (H) DESCRIPTIONS

29

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.
Use Part IV and Schedule I-1 (Form 990) 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 FOR INDIVIDUAL WITH DOWN SYNDROME	7	5,840.	0.		

Part IV Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information**PART II, LINE 1, COLUMN (H):****NAME OF ORGANIZATION OR GOVERNMENT:**

REGENTS OF THE UNIVERSITY OF CALIFORNIA

(H) PURPOSE OF GRANT OR ASSISTANCE: RESEARCH ON THE RELIABILITY OF

TELEMEDICINE IN THE DIAGNOSTICS OF DEMENTIA IN DOWN SYNDROME.

**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

2009

Open to Public Inspection

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number

13-2992567

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.

- | | |
|--|--|
| ☐ First-class or charter travel | ☐ Housing allowance or residence for personal use |
| ☐ Travel for companions | ☐ Payments for business use of personal residence |
| ☐ Tax indemnification and gross-up payments | ☐ Health or social club dues or initiation fees |
| ☐ Discretionary spending account | ☐ 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 organization uses to establish the compensation of the organization's CEO/Executive Director. Check all that apply.

- | | |
|--|--|
| ☒ Compensation committee | ☐ Written employment contract |
| ☐ Independent compensation consultant | ☐ Compensation survey or study |
| ☐ Form 990 of other organizations | ☐ 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?
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan?
- c** Participate in, or receive payment from, an equity-based compensation arrangement?

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?
- b** Any related organization?

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?
- b** Any related organization?

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 Regs. 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

1b		
2		
4a		X
4b		X
4c		X
5a		X
5b		X
6a		X
6b		X
7		X
8		X
9		

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

Schedule J (Form 990) 2009

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

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

OMB No 1545-0047

2009

Open to Public Inspection

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number

13-2992567

Part I Types of Property

	(a) Check if applicable	(b) Number of contributions	(c) Revenues reported on Form 990, Part VIII, line 1g	(d) Method of determining revenues
1 Art - Works of art				
2 Art - Historical treasures				
3 Art - Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded				
10 Securities - Closely held stock				
11 Securities - Partnership, LLC, or trust interests				
12 Securities - Miscellaneous				
13 Qualified conservation contribution - Historic structures				
14 Qualified conservation contribution - Other				
15 Real estate - Residential				
16 Real estate - Commercial				
17 Real estate - Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ► (<u>AUCTION/RAFFL</u>)	X	109	89,070.	FAIR MARKET VALUE AS
26 Other ► (<u>GIFTS</u>)	X	12	34,826.	DETERMINED BY DONOR
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 Acknowledgment

29

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?

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?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

b If "Yes," describe in Part II.

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

	Yes	No
30a		X
31	X	
32a		X
33		

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Schedule M (Form 990) 2009

Part II

Supplemental Information. Complete this part to provide the information required by Part I, lines 30b, 32b, and 33.
Also complete this part for any additional information.

SCHEDULE M, LINE 32B: METHOD OF DETERMINING REVENUES - THE NATIONAL
DOWN SYNDROME SOCIETY ("NDSS") REQUESTS THAT ALL DONORS OF NONCASH
CONTRIBUTIONS PROVIDE A RETAIL VALUE OF THEIR PRODUCT. IF THE VALUE IS
NOT PROVIDED OR IS CONSIDERED PRICELESS, NDSS RESEARCHES THE ITEM ON
THE INTERNET AND DETERMINES A FAIR PRICE. IN MOST CASES, THERE IS A
MARKET VALUE AVAILABLE, AND IN OTHER CASES WE FIND A COMPARABLE ITEM ON
EBAY (OR ANOTHER ONLINE AUCTION SITE) TO DETERMINE THE VALUE. FOOD AND
BEVERAGE DONATIONS, AS WELL AS GIFT BAG ITEMS, ARE VALUED PER PIECE.

SCHEDULE O
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990.

OMB No 1545-0047

2009

Open to Public
Inspection

Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number
13-2992567

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

PUBLIC AWARENESS - THROUGHOUT THE YEAR NDSS PROACTIVELY REACHES OUT TO
THE PUBLIC THROUGH TELEVISION, RADIO, PRINT, NEWSPAPER, ONLINE, AS WELL
AS VARIOUS FORMS OF SOCIAL MEDIA. THROUGH THE MY GREAT STORY PUBLIC
AWARENESS CAMPAIGN, NDSS SECURED OVER \$4 MILLION IN DONATED AD SPACE
AND REACHED AN AUDIENCE OF OVER 150 MILLION. NDSS MAINTAINS NDSS.ORG
AND BUDDYWALK.ORG WHICH TOGETHER GENERATE OVER \$2 MILLION IMPRESSIONS.

RESEARCH - NDSS FUNDED A STUDY, WHICH ESTABLISHED RELIABILITY MEASURES
FOR THE DIAGNOSIS OF DEMENTIA OF THE ALZHEIMER TYPE (DAT) IN DOWN
SYNDROME BY TELEMEDICINE.

EXPENSES \$ 346382. INCLUDING GRANTS OF \$ 54221. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 8B: MINUTES OF THE FINANCE COMMITTEE
WERE PREVIOUSLY NOT DOCUMENTED. THESE MINUTES ARE BEING DOCUMENTED DURING
THE CURRENT FISCAL YEAR.

FORM 990, PART VI, SECTION B, LINE 11: THE DRAFT FORM 990 IS REVIEWED IN
DETAIL BY THE AUDIT COMMITTEE AND THEN GIVEN TO THE ENTIRE BOARD TO READ.

FORM 990, PART VI, SECTION B, LINE 12C: BOARD MEMBERS ARE REQUIRED TO
ANNUALLY AFFIRM COMPLIANCE WITH THE CONFLICT OF INTEREST POLICY.

FORM 990, PART VI, SECTION B, LINE 15A: THE PROCESS FOR DETERMINING THE
PRESIDENT'S SALARY INCLUDES OBTAINING COMPARABILITY DATA, APPROVAL BY THE
EXECUTIVE COMPENSATION COMMITTEE. THERE ARE NO OTHER KEY EMPLOYEES.

SCHEDULE O
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990.

OMB No 1545-0047

2009

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Name of the organization

NATIONAL DOWN SYNDROME SOCIETY

Employer identification number
13-2992567

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

NY,AL,AK,AZ,AR,CA,CO,CT,FL,GA,IL,KS,KY,ME,MD,MA,MI,MN,MS,NH,NJ,NC,ND,OH,OK
PA,RI,SC,TN,UT,VA,WA,WI,WV,NM,OR

FORM 990, PART VI, SECTION C, LINE 19: THE ORGANIZATION'S GOVERNING
DOCUMENTS, CONFLICT OF INTEREST POLICY AND FINANCIAL STATEMENTS ARE
AVAILABLE UPON REQUEST. FINANCIAL STATEMENTS AND IRS FORM 990 ARE ALSO
POSTED ON THE ORGANIZATION'S WEB SITE.

FORM 990, PART XI, LINE 2C

NO CHANGES TO THE PROCESS DURING THE YEAR

**Application for Extension of Time To File an
Exempt Organization Return**

OMB No. 1545-1709

▶ File a separate application for each return.

- If you are filing for an **Automatic 3-Month Extension**, complete only **Part I** and check this box ☒ **X**
- If you are filing for an **Additional (Not Automatic) 3-Month Extension**, complete only **Part II** (on page 2 of this form).

Do not complete **Part II** unless you have already been granted an automatic 3-month extension on a previously filed Form 8868.**Part I Automatic 3-Month Extension of Time.** Only submit original (no copies needed).

A corporation required to file Form 990-T and requesting an automatic 6-month extension - check this box and complete

Part I only ☐

All other corporations (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

Electronic Filing (e-file). Generally, you can electronically file Form 8868 if you want a 3-month automatic extension of time to file one of the returns noted below (6 months for a corporation required to file Form 990-T). However, you cannot file Form 8868 electronically if (1) you want the additional (not automatic) 3-month extension or (2) you file Forms 990-BL, 6069, or 8870, group returns, or a composite or consolidated Form 990-T. Instead, you must submit the fully completed and signed page 2 (Part II) of Form 8868. For more details on the electronic filing of this form, visit www.irs.gov/efile and click on *e-file for Charities & Nonprofits*.

Type or print	Name of Exempt Organization	Employer identification number
	NATIONAL DOWN SYNDROME SOCIETY	13-2992567
	Number, street, and room or suite no. If a P.O. box, see instructions.	
	666 BROADWAY	
File by the due date for filing your return. See instructions.	City, town or post office, state, and ZIP code. For a foreign address, see instructions.	
	NEW YORK, NY 10012	

Check type of return to be filed (file a separate application for each return):

- | | | |
|--|---|------------------------------------|
| ☒ Form 990 | ☐ Form 990-T (corporation) | ☐ Form 4720 |
| ☐ Form 990-BL | ☐ Form 990-T (sec. 401(a) or 408(a) trust) | ☐ Form 5227 |
| ☐ Form 990-EZ | ☐ Form 990-T (trust other than above) | ☐ Form 6069 |
| ☐ Form 990-PF | ☐ Form 1041-A | ☐ Form 8870 |

HARRY JELLINEK

- The books are in the care of ▶ **666 BROADWAY - NEW YORK, NY 10012**
Telephone No. ▶ **(212) 763-4368** FAX No ▶ **(212) 979-2873**
- 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 will cover.

- 1 I request an automatic 3-month (6-months for a corporation required to file Form 990-T) extension of time until **NOVEMBER 15, 2010**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:

▶ ☐ calendar year _____ or
 ▶ ☒ tax year beginning **APR 1, 2009**, and ending **MAR 31, 2010**

- 2 If this tax year is for less than 12 months, check reason: ☐ Initial return ☐ Final return ☐ Change in accounting period

3a 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.	3a	\$
b If this application is for Form 990-PF or 990-T, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit.	3b	\$
c Balance Due. Subtract line 3b from line 3a. Include your payment with this form, or, if required, deposit with FTD coupon or, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.	3c	\$ N/A

Caution. If you are going to make an electronic fund withdrawal with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

LHA For Privacy Act and Paperwork Reduction Act Notice, see Instructions.

Form **8868** (Rev. 4-2009)