



See a Social Security Number? Say Something!
Report Privacy Problems to <https://public.resource.org/privacy>
Or call the IRS Identity Theft Hotline at 1-800-908-4490



Form **990**

Return of Organization Exempt From Income Tax

OMB No 1545-0047

2009

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

A For the 2009 calendar year, or tax year beginning _____, and ending _____

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 ORGANIZATION FOR RARE DISORDERS INC**
 Doing Business As _____
 Number and street (or P O box if mail is not delivered to street address) Room/suite
55 KENOSIA AVENUE
 City or town, state or country, and ZIP + 4
DANBURY CT 06813-1968

D Employer identification number **13-3223946**
E Telephone number **203-744-0100**
G Gross receipts \$ **14,345,830**

F Name and address of principal officer
PETER L. SALTONSTALL 55 KENOSIA AVENUE, DANBURY, CT 06813

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)

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

J Website: **WWW.RAREDISEASES.ORG**

K Form of organization Corporation Trust Association Other ▶

L Year of formation **1983** **M** State of legal domicile **NY**

H(c) Group exemption number ▶

Part I Summary		Prior Year	Current Year
1 Briefly describe the organization's mission or most significant activities: <u>IMPROVE IDENTIFICATION, TREATMENT, AND CURE OF RARE DISEASES THROUGH PROGRAMS OF EDUCATION, ADVOCACY, RESEARCH AND SERVICE.</u>			
2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.			
3 Number of voting members of the governing body (Part VI, line 1a)	3		17
4 Number of independent voting members of the governing body (Part VI, line 1b)	4		17
5 Total number of employees (Part V, line 2a)	5		55
6 Total number of volunteers (estimate if necessary)	6		55
7a Total gross unrelated business revenue from Part VIII, column (C), line 12	7a		0
7b Net unrelated business taxable income from Form 990-T, line 34	7b		0
8 Contributions and grants (Part VIII, line 1h)		10,475,348	12,041,663
9 Program service revenue (Part VIII, line 2g)		1,873,704	2,049,111
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)		524,158	255,056
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		0	0
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)		12,873,210	14,345,830
13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)		8,148,486	10,531,850
14 Benefits paid to or for members (Part IX, column (A), line 4)		0	0
15 Salaries, other compensation, and employee benefits (Part IX, column (A), lines 5–10)		2,214,137	2,460,498
16a Professional fundraising fees (Part IX, column (A), line 11e)		0	0
b Total fundraising expenses (Part IX, column (B), line 25) ▶ 212,175			
17 Other expenses (Part IX, column (A), lines 11a–1d, 11f–24f)		1,376,587	1,239,701
18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)		11,739,210	14,232,049
19 Revenue less expenses. Subtract line 18 from line 12		1,134,000	113,781
20 Total assets (Part X, line 16)		18,902,338	17,771,948
21 Total liabilities (Part X, line 26)		4,340,327	3,005,626
22 Net assets or fund balances. Subtract line 21 from line 20		14,562,011	14,766,322

Part II Signature Block

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

Sign Here
 Signature of officer: *Frank J. Sasinowski* Date: **1/10/2011**
 Frank J. Sasinowski, Chair, Board of Directors
 Type or print name and title

Paid Preparer's Use Only
 Preparer's signature: *Michael Solakian* Date: **1/7/2011**
 Check if self-employed: Preparer's identifying number (see instructions): **P00108306**
 Firm's name (or yours if self-employed): **SOLAKIAN, CAIAFA AND COMPANY, LLC** EIN: **06-1343015**
 address, and ZIP + 4: **71 HARRISON AVENUE, BRANFORD, CT 06405-3607** Phone no: **(203) 483-8115**

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

For Privacy Act and Paperwork Reduction Act Notice, see the separate instructions.

Form **990** (2009)

(HTA)

23 9/6

SCANNED FEB 04 2011

Part III Statement of Program Service Accomplishments

1 Briefly describe the organization's mission:

IMPROVE IDENTIFICATION, TREATMENT, AND CURE OF RARE DISEASES THROUGH PROGRAMS OF EDUCATION, ADVOCACY, RESEARCH AND SERVICE.

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 \$ 11,655,048 including grants of \$ 0) (Revenue \$ 11,326,429)

PATIENT SERVICES-PROVIDES FREE OR LOW COST PRESCRIPTION DRUGS TO UNINSURED AND NEEDY PATIENTS OR PAYMENT OF THEIR HEALTH INSURANCE PREMIUMS OR CO-PAYS

4b (Code:) (Expenses \$ 1,356,469 including grants of \$ 0) (Revenue \$ 0)

EDUCATION-PROVIDE UNDERSTANDABLE INFO TO PATIENTS, FAMILIES AND THE MEDICAL COMMUNITY THROUGH PUBLICATIONS, NEWSLETTERS, BOOKS AND THE NORD RARE DISEASE DATABASE ACCESSIBLE ON THE INTERNET

4c (Code:) (Expenses \$ 263,427 including grants of \$ 0) (Revenue \$ 0)

RESEARCH-PROVIDES ASSISTANCE THROUGH FUNDING OF VARIOUS RESEARCH GRANTS TO ACADEMIC SCIENTISTS DEVELOPING NEW TREATMENTS AND DIAGNOSTICS FOR RARE DISORDERS

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

(Expenses \$ 176,990 including grants of \$ 0) (Revenue \$ 0)

4e Total program service expenses ▶ 13,451,934

Part IV Checklist of Required Schedules

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors?	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities? <i>If "Yes," complete Schedule C, Part II</i>	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>		
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>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9	Did the organization report an amount in Part X, line 21; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10	Did the organization, directly or through a related organization, hold assets in term, permanent, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>		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>	X	
	<ul style="list-style-type: none"> • 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>	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>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
14b	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>	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>	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>		X
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>		X
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	X	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20	Did the organization operate one or more hospitals? <i>If "Yes," complete Schedule H</i>		X

Part IV Checklist of Required Schedules (continued)

	Yes	No
21 Did the organization report more than \$5,000 of grants and other assistance to 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>	X	
22 Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	X	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	X	
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25</i>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		X
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?		X
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		X
25a Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>		X
26 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>		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>		X
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
c An entity of which a current or former officer, director, trustee, or key employee 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>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>		X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>		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>		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>		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>		X
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O	X	

Part V Statements Regarding Other IRS Filings and Tax Compliance

Table with columns for question number, description, and Yes/No response. Includes questions 1a-12a regarding IRS filings, employee reporting, foreign accounts, and charitable trusts.

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			
FRANK J. SASINOWSKI CHAIRMAN	2.	X		X				0	0	0
CARLOYN ASBURY VICE CHAIR	2.	X		X				0	0	0
JOSEPHINE GRIMA SECRETARY	2.	X		X				0	0	0
STEPHEN BAJARDI TREASURER	2.	X		X				0	0	0
WENDY WHITE DIRECTOR	2.	X						0	0	0
JAMES BROATCH DIRECTOR	2.	X						0	0	0
CLAIRE A. CENTRELLA DIRECTOR	2.	X						0	0	0
BRENDA DUFFY DIRECTOR	2.	X						0	0	0
NANCY HARRIS DIRECTOR	2.	X						0	0	0
CHRISTOPHER JENNINGS DIRECTOR	2.	X						0	0	0
EMIL KAKKIS DIRECTOR	2.	X						0	0	0
MARYBETH KRUMMENACKER DIRECTOR	2.	X						0	0	0
DESIREE LYON DIRECTOR	2.	X						0	0	0
MARY SPRAGUE DIRECTOR	2.	X						0	0	0
JUDIT UNGAR DIRECTOR	2.	X						0	0	0
AGNES VARIS DIRECTOR	2.	X						0	0	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	1a Federated campaigns	1a 57,347				
	b Membership dues	1b 55,246				
	c Fundraising events	1c 697,600				
	d Related organizations	1d 0				
	e Government grants (contributions)	1e 0				
	f All other contributions, gifts, grants, and similar amounts not included above	1f 11,231,470				
	g Noncash contributions included in lines 1a-1f: \$	0				
	h Total. Add lines 1a-1f	▶ 12,041,663				
Program Service Revenue	Business Code					
	2a INDIGENT CARE DRUG PROGRAMS	900099	1,937,906	1,937,906		
	b ROYALTY AND OTHER INCOME	900099	55,735	55,735		
	c LITERATURE AND MATERIALS	900099	55,470	55,470		
	d		0			
	e		0			
	f All other program service revenue		0			
g Total. Add lines 2a-2f	▶ 2,049,111					
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)	▶ 255,056			255,056	
	4 Income from investment of tax-exempt bond proceeds	▶ 0				
	5 Royalties	▶ 0				
	6a Gross Rents	(i) Real	(ii) Personal			
		b Less: rental expenses				
	c Rental income or (loss)	0	0			
	d Net rental income or (loss)	▶ 0				
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
		0	0			
		b Less: cost or other basis and sales expenses	0	0		
		c Gain or (loss)	0	0		
	d Net gain or (loss)	▶ 0				
	8a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18	a				
		b Less: direct expenses	b 0			
c Net income or (loss) from fundraising events		▶ 0				
9a Gross income from gaming activities. See Part IV, line 19	a	0				
	b Less: direct expenses	b 0				
	c Net income or (loss) from gaming activities	▶ 0				
10a Gross sales of inventory, less returns and allowances	a	0				
	b Less: cost of goods sold	b 0				
	c Net income or (loss) from sales of inventory	▶ 0				
Miscellaneous Revenue		Business Code				
11a			0			
b			0			
c			0			
d All other revenue			0			
e Total. Add lines 11a-11d	▶ 0					
12 Total revenue. See instructions	▶ 14,345,830		2,049,111	0	255,056	

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).

<i>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</i>	(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	233,000	233,000		
2 Grants and other assistance to individuals in the U.S. See Part IV, line 22	10,198,850	10,198,850		
3 Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16	100,000	100,000		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	228,906	14,399	214,507	
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0			
7 Other salaries and wages	1,787,135	1,709,921	0	77,214
8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)	0			
9 Other employee benefits	292,401	185,138	85,241	22,022
10 Payroll taxes	152,056	96,923	36,909	18,224
11 Fees for services (non-employees):				
a Management	0			
b Legal	0			
c Accounting	0			
d Lobbying	0			
e Professional fundraising services. See Part IV, line 17	0			
f Investment management fees	0			
g Other	160,761	141,713	14,552	4,496
12 Advertising and promotion	27,535	27,535	0	0
13 Office expenses	50,807	41,700	6,171	2,936
14 Information technology	51,637	41,791	7,383	2,463
15 Royalties	0			
16 Occupancy	108,557	77,123	21,402	10,032
17 Travel	117,324	46,964	69,603	757
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19 Conferences, conventions, and meetings	296,092	273,715	0	22,377
20 Interest	48,009	29,058	13,079	5,872
21 Payments to affiliates	0			
22 Depreciation, depletion, and amortization	64,577	34,078	22,570	7,929
23 Insurance	14,655	9,404	3,467	1,784
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 NEWSLETTER AND DIRECT MAIL EXPENSE	78,746	57,527	0	21,219
b POSTAGE AND SHIPPING	52,700	39,030	10,764	2,906
c REPAIRS AND MAINTENANCE	47,387	35,320	8,642	3,425
d PROFESSIONAL FEES	45,245	29,500	15,745	0
e DUES, SUBSCRIPTIONS AND REGISTRATIONS	42,298	13,617	23,992	4,689
f All other expenses MISCELLANEOUS	33,371	15,628	13,913	3,830
25 Total functional expenses. Add lines 1 through 24f	14,232,049	13,451,934	567,940	212,175
26 Joint costs. Check here <input checked="" type="checkbox"/> 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	354,382	313,817	0	40,565

Part X Balance Sheet

		(A)		(B)
		Beginning of year		End of year
Assets	1 Cash—non-interest-bearing	250	1	250
	2 Savings and temporary cash investments	16,998,603	2	15,382,522
	3 Pledges and grants receivable, net	1,250	3	39,300
	4 Accounts receivable, net	0	4	0
	5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L	0	5	0
	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	0	6	0
	7 Notes and loans receivable, net	0	7	0
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	17,480	9	51,287
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 2,225,791		
	b Less: accumulated depreciation	10b 670,793	10c	1,554,998
	11 Investments—publicly traded securities	643,033	11	738,412
	12 Investments—other securities. See Part IV, line 11	0	12	0
	13 Investments—program-related. See Part IV, line 11	0	13	0
	14 Intangible assets	0	14	0
	15 Other assets. See Part IV, line 11	2,445	15	5,179
16 Total assets. Add lines 1 through 15 (must equal line 34)	18,902,338	16	17,771,948	
Liabilities	17 Accounts payable and accrued expenses	94,076	17	60,247
	18 Grants payable	459,638	18	517,108
	19 Deferred revenue	2,935,250	19	1,613,150
	20 Tax-exempt bond liabilities	0	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	0	22	
	23 Secured mortgages and notes payable to unrelated third parties	851,363	23	815,121
	24 Unsecured notes and loans payable to unrelated third parties	0	24	0
	25 Other liabilities. Complete Part X of Schedule D	0	25	0
	26 Total liabilities. Add lines 17 through 25	4,340,327	26	3,005,626
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	4,343,769	27	6,238,552
	28 Temporarily restricted net assets	10,218,242	28	8,527,770
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	14,562,011	33	14,766,322
34 Total liabilities and net assets/fund balances	18,902,338	34	17,771,948	

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		

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support

OMB No. 1545-0047

2009

Open to Public Inspection

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.

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

Name of the organization

Employer identification number

NATIONAL ORGANIZATION FOR RARE DISORDERS INC.

13-3223946

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?

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

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

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1–9 above or IRC section (see Instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U.S.?		(vii) Amount of support
			Yes	No	Yes	No	Yes	No	
									0
									0
									0
									0
									0
									0
Total									0

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.")	0	0				0
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf	0	0				0
3 The value of services or facilities furnished by a governmental unit to the organization without charge	0	0				0
4 Total. Add lines 1 through 3	0	0	0	0	0	0
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4						0

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4	0	0	0	0	0	0
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	0	0				0
9 Net income from unrelated business activities, whether or not the business is regularly carried on						0
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	0	0				0
11 Total support. Add lines 7 through 10						0
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2009 (line 6, column (f) divided by line 11, column (f))	14	0.00%
15 Public support percentage from 2008 Schedule A, Part II, line 14	15	0.00%
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 ▶ <input type="checkbox"/>		
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 ▶ <input type="checkbox"/>		
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. ▶ <input type="checkbox"/>		
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 ▶ <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ▶ <input type="checkbox"/>		

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

(Complete only if you checked the box on line 9 of Part I.)

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.")	12,933,637	11,653,938	11,438,927	10,475,348	12,041,663	58,543,513
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	1,745,229	2,672,826	2,272,759	1,873,704	2,049,111	10,613,629
3 Gross receipts from activities that are not an unrelated trade or business under section 513						0
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf	0	0	0	0		0
5 The value of services or facilities furnished by a governmental unit to the organization without charge	0	0	0	0		0
6 Total. Add lines 1 through 5	14,678,866	14,326,764	13,711,686	12,349,052	14,090,774	69,157,142
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						0
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						0
c Add lines 7a and 7b	0	0	0	0	0	0
8 Public support (Subtract line 7c from line 6.)						69,157,142

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	14,678,866	14,326,764	13,711,686	12,349,052	14,090,774	69,157,142
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	215,052	453,004	617,658	524,158	255,056	2,064,928
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						0
c Add lines 10a and 10b	215,052	453,004	617,658	524,158	255,056	2,064,928
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						0
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	0	0				0
13 Total support. (Add lines 9, 10c, 11, and 12.)	14,893,918	14,779,768	14,329,344	12,873,210	14,345,830	71,222,070
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 ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2009 (line 8, column (f) divided by line 13, column (f))	15	97.10%
16 Public support percentage from 2008 Schedule A, Part III, line 15	16	97.00%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2009 (line 10c, column (f) divided by line 13, column (f))	17	2.90%
18 Investment income percentage from 2008 Schedule A, Part III, line 17	18	3.00%

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 ▶

Political Campaign and Lobbying Activities

2009

Open to Public Inspection

For Organizations Exempt From Income Tax Under section 501(c) and section 527

▶ Complete if the organization is described below.

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

Department of the Treasury
Internal Revenue Service

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 ORGANIZATION FOR RARE DISORDERS INC.	Employer identification number 13-3223946
------------------------------------------------------------------------------	-----------------------------------------------------

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 ▶ \$0
- 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-
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0

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

- A Check if the filing organization belongs to an affiliated group.
 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)		0												
b	Total lobbying expenditures to influence a legislative body (direct lobbying)		0												
c	Total lobbying expenditures (add lines 1a and 1b)	0	0												
d	Other exempt purpose expenditures		0												
e	Total exempt purpose expenditures (add lines 1c and 1d)	0	0												
f	Lobbying nontaxable amount. Enter the amount from the following table in both columns.	0	0												
<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)	0	0												
h	Subtract line 1g from line 1a. If zero or less, enter -0-	0	0												
i	Subtract line 1f from line 1c. If zero or less, enter -0-	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?		<input type="checkbox"/> Yes <input type="checkbox"/> No												

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

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) Total
2a	Lobbying nontaxable amount	0	0	0	0
b	Lobbying ceiling amount (150% of line 2a, column(e))				0
c	Total lobbying expenditures	0	0	0	0
d	Grassroots nontaxable amount	0	0	0	0
e	Grassroots ceiling amount (150% of line 2d, column (e))				0
f	Grassroots lobbying expenditures	0	0	0	0

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

	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?	X		
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	X		
c Media advertisements?		X	
d Mailings to members, legislators, or the public?	X		871
e Publications, or published or broadcast statements?	X		884
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?	X		503
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?	X		
i Other activities? If "Yes," describe in Part IV		X	
j Total. Add lines 1c through 1i			2,258
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

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

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

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

1 Dues, assessments and similar amounts from members	1	
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
a Current year	2a	
b Carryover from last year	2b	
c Total	2c	0
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	0

Part IV Supplemental Information

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

2009

Open to Public Inspection

Name of the organization

Employer identification number

NATIONAL ORGANIZATION FOR RARE DISORDERS INC.

13-3223946

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

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

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

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

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or pleasure)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> 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 exhibition
- b Scholarly research
- c Preservation for future generations
- d Loan or exchange programs
- e Other

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part 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 the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No

b If "Yes," explain the arrangement in Part XIV and complete the following table:

	Amount
c Beginning balance	0
d Additions during the year	
e Distributions during the year	
f Ending balance	0

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	0				
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance	0	0			

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

- a Board designated or quasi-endowment %
- b Permanent endowment %
- 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

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

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.

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	0	505,203		505,203
b Buildings	0	761,597	118,930	642,667
c Leasehold improvements	0	11,910	1,588	10,322
d Equipment	0	947,081	550,275	396,806
e Other	0	0	0	0
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c))				1,554,998

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)	14,345,830
2	Total expenses (Form 990, Part IX, column (A), line 25)	14,232,049
3	Excess or (deficit) for the year. Subtract line 2 from line 1	113,781
4	Net unrealized gains (losses) on investments	
5	Donated services and use of facilities	
6	Investment expenses	
7	Prior period adjustments	
8	Other (Describe in Part XIV.)	
9	Total adjustments (net). Add lines 4 through 8	0
10	Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9	113,781

Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return		
1	Total revenue, gains, and other support per audited financial statements	14,436,360
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:	
a	Net unrealized gains on investments	90,530
b	Donated services and use of facilities	
c	Recoveries of prior year grants	
d	Other (Describe in Part XIV.)	
e	Add lines 2a through 2d	90,530
3	Subtract line 2e from line 1	14,345,830
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	
b	Other (Describe in Part XIV.)	
c	Add lines 4a and 4b	0
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	14,345,830

Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return		
1	Total expenses and losses per audited financial statements	14,232,049
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:	
a	Donated services and use of facilities	
b	Prior year adjustments	
c	Other losses	
d	Other (Describe in Part XIV.)	
e	Add lines 2a through 2d	0
3	Subtract line 2e from line 1	14,232,049
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	
b	Other (Describe in Part XIV.)	
c	Add lines 4a and 4b	0
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)	14,232,049

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 X Line 2 The Organization elected to defer the application of FIN 48 to its year

ending December 31, 2009. Management has determined that the adoption of FIN 48 will not

have a material impact on its financial statements.

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	
		BANQUET (event type)	AL SUMMIT/CONFEE (event type)	NONE (total number)	(add col (a) through col. (c))	
Revenue	1	Gross receipts	582,600	115,000	0	697,600
	2	Less: Charitable contributions	0	0	0	0
	3	Gross income (line 1 minus line 2)	582,600	115,000	0	697,600
Direct Expenses	4	Cash prizes	0	0	0	0
	5	Noncash prizes	0	0	0	0
	6	Rent/facility costs	0	0	0	0
	7	Food and beverages	0	0	0	0
	8	Entertainment	0	0	0	0
	9	Other direct expenses	0	0	0	0
	10	Direct expense summary. Add lines 4 through 9 in column (d) ▶				
11	Net income summary. Combine line 3, column (d), and line 10 ▶					697,600

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			0		
Direct Expenses	2	Cash prizes			0		
	3	Noncash prizes			0		
	4	Rent/facility costs			0		
	5	Other direct expenses			0		
	6	Volunteer labor	<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	<input type="checkbox"/> Yes _____% <input type="checkbox"/> No		
	7	Direct expense summary. Add lines 2 through 5 in column (d) ▶					(0)
	8	Net gaming income summary. Combine line 1, column d, and line 7 ▶					0

	Yes	No
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?	9a	
b If "No," explain: _____		
10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?	10a	
b If "Yes," explain: _____		
11 Does the organization operate gaming activities with nonmembers?	11	
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?	12	

		Yes	No
13	Indicate the percentage of gaming activity operated in:		
a	The organization's facility 13a %		
b	An outside facility 13b %		
14	Enter the name and address of the person who prepares the organization's gaming/special events books and records:		
	Name ▶		
	Address ▶		
15a	Does the organization have a contract with a third party from whom the organization receives gaming revenue? 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 ▶ \$ 0		
	Description of services provided ▶		
	<input type="checkbox"/> Director/officer <input type="checkbox"/> Employee <input type="checkbox"/> 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 ▶ \$		

**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 ORGANIZATION FOR RARE DISORDERS INC.

Employer identification number

13-3223946

Part I Questions Regarding Compensation

1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed in Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

- | | |
|--------------------------------------------------------------------|--------------------------------------------------------------------------|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef) |

b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

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

3 Indicate which, if any, of the following the organization uses to establish the compensation of the organization's CEO/Executive Director. Check all that apply.

- | | |
|--------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <input type="checkbox"/> Compensation committee | <input type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input type="checkbox"/> Compensation survey or study |
| <input type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

4 During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a** Receive a severance payment or change-of-control payment?
- 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
1a		
1b		
2		
3		
4a		X
4b		X
4c		X
5a		X
5b		X
6a		X
6b		X
7		X
8		X
9		

**SCHEDULE O
(Form 990)**

Department of the Treasury
Internal Revenue Service

Name of the organization

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

Employer identification number

NATIONAL ORGANIZATION FOR RARE DISORDERS INC.

13-3223946

Form 990, Part III, Line 4d: Program Service Expenses: 92,413, Grants and allocations: 0,

Revenue: 0 TECHNICAL ASSISTANCE-PROVIDE ASSISTANCE TO VOLUNTARY HEALTH AGENCIES AND SUPPORT

GROUPS TO IMPROVE THEIR EFFECTIVENESS, COMPLIANCE WITH NON-PROFIT STANDARDS AND PROGRAM

DEVELOPMENT

Form 990, Part III, Line 4d: Program Service Expenses: 84,577, Grants and allocations: 0,

Revenue: 0 ADVOCACY

Form 990 Part VI Section B Line 11a REVIEWED BY CFO, CEO, TREASURER, FINANCE COMMITTEE,

EXECUTIVE COMMITTEE AND CHAIRPERSON OF THE AUDIT COMMITTEE PRIOR TO BEING FILED

Form 990 Part VI Section B Line 12 BOD REVIEWS ALL CONFLICT OF INTEREST MATTERS AND

DOCUMENTS WHEN APPROPRIATE.

Form 990 Part VI Section B Line 15 BOD REVIEWS THIRD PARTY INFO AS WELL AS PUBLISHED SALARY

RANGES

Form 990 Part VI Section C Line 19 GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND

FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST.

Form 990 SEE ATTACHED LIST FOR ALL STATES WHERE FORM 990 IS FILED.

Form 990 Part I Line 3,4 AMENDED RETURN IS BEING FILED FOR CHANGE IN VOTING AND INDEPENDENT

VOTING MEMBERS TO 17

Form 990 Part VII Section A Line 1 AMENDED RETURN IS BEING FILED IN ORDER TO SHOW ALL

DIRECTORS IN PART VII INSTEAD OF IN AN ATTACHED SCHEDULE

Part VI, Line 17 (990) - States with Which a Copy of this Form 990 is Required to be Filed

<input type="checkbox"/>	Armed Forces the Americas	<input type="checkbox"/>	Louisiana	<input type="checkbox"/>	Palau
<input type="checkbox"/>	Armed Forces Europe	<input checked="" type="checkbox"/>	Massachusetts	<input checked="" type="checkbox"/>	Rhode Island
<input checked="" type="checkbox"/>	Alaska	<input checked="" type="checkbox"/>	Maryland	<input checked="" type="checkbox"/>	South Carolina
<input checked="" type="checkbox"/>	Alabama	<input checked="" type="checkbox"/>	Maine	<input type="checkbox"/>	South Dakota
<input type="checkbox"/>	Armed Forces Pacific	<input type="checkbox"/>	Marshall Islands	<input checked="" type="checkbox"/>	Tennessee
<input type="checkbox"/>	Arkansas	<input checked="" type="checkbox"/>	Michigan	<input type="checkbox"/>	Texas
<input type="checkbox"/>	American Samoa	<input checked="" type="checkbox"/>	Minnesota	<input checked="" type="checkbox"/>	Utah
<input checked="" type="checkbox"/>	Arizona	<input type="checkbox"/>	Missouri	<input checked="" type="checkbox"/>	Virginia
<input checked="" type="checkbox"/>	California	<input type="checkbox"/>	Commonwealth of the Northern Mariana Islands	<input type="checkbox"/>	U.S. Virgin Islands
<input checked="" type="checkbox"/>	Colorado	<input checked="" type="checkbox"/>	Mississippi	<input type="checkbox"/>	Vermont
<input checked="" type="checkbox"/>	Connecticut	<input type="checkbox"/>	Montana	<input checked="" type="checkbox"/>	Washington
<input checked="" type="checkbox"/>	District of Columbia	<input checked="" type="checkbox"/>	North Carolina	<input checked="" type="checkbox"/>	Wisconsin
<input type="checkbox"/>	Delaware	<input type="checkbox"/>	North Dakota	<input checked="" type="checkbox"/>	West Virginia
<input checked="" type="checkbox"/>	Florida	<input type="checkbox"/>	Nebraska	<input type="checkbox"/>	Wyoming
<input type="checkbox"/>	Federated States of Micronesia	<input checked="" type="checkbox"/>	New Hampshire		
<input checked="" type="checkbox"/>	Georgia	<input checked="" type="checkbox"/>	New Jersey		
<input type="checkbox"/>	Guam	<input checked="" type="checkbox"/>	New Mexico		
<input type="checkbox"/>	Hawaii	<input checked="" type="checkbox"/>	Nevada		
<input type="checkbox"/>	Iowa	<input checked="" type="checkbox"/>	New York		
<input type="checkbox"/>	Idaho	<input checked="" type="checkbox"/>	Ohio		
<input checked="" type="checkbox"/>	Illinois	<input checked="" type="checkbox"/>	Oklahoma		
<input checked="" type="checkbox"/>	Indiana	<input checked="" type="checkbox"/>	Oregon		
<input checked="" type="checkbox"/>	Kansas	<input checked="" type="checkbox"/>	Pennsylvania		
<input checked="" type="checkbox"/>	Kentucky	<input type="checkbox"/>	Puerto Rico		

Elections

Election to NOT claim first-year special depreciation - All Property

The Taxpayer elects out of first-year special depreciation for all depreciable property placed in service during the current tax year.

Part VIII, Lines 1a-h (990) - Contributions, Gifts, Grants, and Other Amounts

	Cash	Noncash
1 Federated Campaigns	57,347	1
2 Membership dues	55,246	2
3 Fundraising events	697,600	3
4 Related organizations		4
5 Government grants (contributions)		5
6 All other contributions, gifts, grants, and similar amounts not included above:		
CONTRIBUTIONS AND BEQUESTS	785,814	
CONTRIBUTIONS AND GRANTS	10,445,656	
Other contributions total	11,231,470	6
7 Total	12,041,663	7

Part IX, Line 22 (990) - Depreciation, Depletion, and Amortization

	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
1 Depreciation	64,577	34,078	22,570	7,929
2 Depletion	0			
3 Amortization	0			
4 Total	64,577	34,078	22,570	7,929

Part X, Line 3 (990) - Pledges and Grants Receivable

		Pledges and grants receivable		Allowance for doubtful accounts	
		Beginning	End	Beginning	End
1 Grants receivable	1	1,250	39,300	0	0
2	2				
3	3				
4	4				
5	5				
6	6				
7	7				
8	8				
9	9				
10	10				
11 Total pledges and grants receivable	11	1,250	39,300	0	0

Part X, Lines 10a and 10b (990) - Land, Buildings, and Equipment

Category or Item		Land	Buildings	Leasehold Improvements	Equipment	Other	Check if Investment Asset	Check if Asset Disposed	Cost/Other Basis	Beginning Accumulated Depreciation	Ending Accumulated Depreciation	Disposals/ Adjustments	Beginning Balance	Ending Balance
1	LAND	X							505,203	0	0		505,203	505,203
2	BUILDINGS		X						744,797	97,793	116,410		647,004	628,387
3	BUILDING IMPROVEMENTS		X						16,800	1,680	2,520		15,120	14,280
4	EQUIPMENT				X				947,081	505,152	550,275		71,950	396,806
5	LEASEHOLD IMPROVEMENTS			X					11,910	0	1,588		0	10,322
6									0	0	0		0	0
7									0	0	0		0	0
8									0	0	0		0	0
9									0	0	0		0	0
10									0	0	0		0	0
11									0	0	0		0	0
12									0	0	0		0	0
13									0	0	0		0	0
14									0	0	0		0	0
15									0	0	0		0	0
16									0	0	0		0	0
17									0	0	0		0	0
18									0	0	0		0	0
19									0	0	0		0	0
20									0	0	0		0	0
21									0	0	0		0	0
22									0	0	0		0	0
23									0	0	0		0	0
24									0	0	0		0	0
25									0	0	0		0	0
26									0	0	0		0	0
27									0	0	0		0	0
28									0	0	0		0	0
29									0	0	0		0	0
30									0	0	0		0	0
31									0	0	0		0	0
32									0	0	0		0	0
33									0	0	0		0	0
34									0	0	0		0	0
35									0	0	0		0	0
36									0	0	0		0	0
37									0	0	0		0	0
38									0	0	0		0	0
39									0	0	0		0	0
40									0	0	0		0	0
									2,225,791	604,625	670,793	0	1,239,277	1,554,998

Part X, Lines 11 and 12 (990) - Investments - Securities

Check one box below to indicate how securities are reported:

Cost

End of year market value (FMV)

0 643,033 738,412

	Description	Check if Publicly Traded Securities?	Check if Financial Derivatives	Check if Closely-Held Equity Interests	Number of Shares/Face Value	Value at Time of Donation	Beginning Balance Book Value FMV	Ending Balance Book Value FMV
1	CORPORATE BONDS	X			VARIOUS	0	458,943	538,771
2	MUTUAL FUNDS	X			VARIOUS	0	184,090	199,641
3					0.00	0	0	0
4					0.00	0	0	0
5					0.00	0	0	0
6					0.00	0	0	0
7					0.00	0	0	0
8					0.00	0	0	0
9					0.00	0	0	0
10					0.00	0	0	0
11					0.00	0	0	0
12					0.00	0	0	0
13					0.00	0	0	0
14					0.00	0	0	0
15					0.00	0	0	0
16					0.00	0	0	0
17					0.00	0	0	0
18					0.00	0	0	0
19					0.00	0	0	0
20					0.00	0	0	0

Part X, Line 15 (990) - Other Assets

2,445

5,179

	Description	Beginning	End
1	SECURITY DEPOSITS	2,445	5,179
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			

Part X, Lines 23 and 24 (990) - Secured and Unsecured Notes Payable

			851,363	815,121
	Lender's name	Check if Unsecured	Balance due beginning of year	Balance due end of year
1	UNION SAVINGS BANK		851,363	815,121
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Part XIV (Sch D (990)) - Supplemental Information

Part	Line Number	Explanation
1	X 2	The Organization elected to defer the application of FIN 48 to its year ending December 31, 2009. Management has determined that the adoption of FIN 48 will not have a material impact on its financial statements.
2		

Part I, Line 3 (Sch F, F-1 (990)) - Activities per Region

	Region	Number of offices in the region	Number of employees or agents in region	Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	If activity listed is a program service, describe specific type of service(s) in region	Total expenditures in region
1	Europe			GRANTS TO RECIPIENTS	RESEARCH GRANT	100,000
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						
16						
17						
18						
19						
20						

Part III (Sch I, I-1 (990)) - Grants and Other Assistance to Individuals in the US

	Type of Grant	Number of Recipients	Amount of Cash Grant	Amount of		Method of Valuation	Description of
				Cash Grant	Non-Cash Assistance		
1	INSURANCE PREMIUM CO-PAYMENTS	5,000	10,198,850	0	FMV	N/A	
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							
12							
13							
14							
15							
16							
17							
18							
19							
20							

Assets by Classification - 990

12/31/2009 NATIONAL ORGANIZATION FOR RARE DISORDERS INC 13-3223946

Item No	Description of Property *** indicates SOLD	Date Placed In Service	Asset Code	Bus Use %	Cost or Other Basis	Sec. 179 Deduction	Special Allowance	Salvage Value	Recovery Basis	Recovery Period	Method	Conv Code	Prior Accum Deprec. 179 Bonus	2009 Deprec.	2009 Accum. Deprec.
5-yr Computers (not listed)															
5	ALL OTHER ASSETS	1/1/2000	F-5	100.00%	445,636	0	0	0	445,636	5	SL/GDS	HY	441,932	4,265	446,197
3	COMPUTERS	2/1/2004	F-5	100.00%	16,944	0	0	0	16,944	5	SL/GDS	HY	16,944	0	16,944
4	COMPUTERS-2005	7/1/2005	F-5	100.00%	27,274	0	0	0	27,274	5	SL/GDS	HY	21,820	5,454	27,274
6	COMPUTERS	7/1/2006	F-5	100.00%	13,010	0	0	0	13,010	5	SL	HY	7,806	2,602	10,408
7	EQUIPMENT	7/1/2007	F-5	100.00%	5,632	0	0	0	5,632	5	SL	HY	2,928	1,126	4,054
10	EQUIPMENT-VAR	7/1/2009	F-5	100.00%	141,064	0	0	0	141,064	5	SL/GDS	FM	0	16,765	16,765
Total: 5-yr Computers and peripherals (not listed proper)													491,430	30,212	521,642
5-yr Office mach (data handling)															
9	EQUIPMENT ETC.	7/1/2008	F-6	100.00%	68,605	0	0	0	68,605	5	SL	HY	13,721	13,721	27,442
Total: 5-yr Office machinery (data-handling equipment, ...)													68,605	0	68,605
7-yr Genl purp tools, mach, equip															
11	TELEPHONE EQUIP	10/1/2009	F-10	100.00%	47,514	0	0	0	47,514	10	SL/GDS	FM	0	1,184	1,184
Total: 7-yr General purpose tools, machinery, and equip...													47,514	0	47,514
Land															
2	LAND	2/1/2004	N-1	100.00%	505,203	0	0	0	505,203				0	0	0
Total: Land													505,203	0	505,203
15-yr Qual leasehold improvement prop															
8	BLDG IMPROV	12/31/2006	R-7	100.00%	16,800	0	0	0	16,800	20	SL/GDS	HY	1,680	840	2,520
Total: 15-yr Qual LH improv													16,800	0	16,800
39-yr Nonresidential real estate															
1	BUILDING	2/1/2004	R-5	100.00%	744,797	0	0	0	744,797	40	SL/GDS	MM	97,793	18,620	116,413
Total: 39-yr Nonresidential and commercial real estate													744,797	0	744,797
SubTotals													2,032,479	0	2,032,479
Less: Assets Sold													(0)	(0)	(0)
Ending Totals													2,032,479	0	2,032,479

604,624	64,577	669,201
(0)	(0)	(0)
604,624	64,577	669,201

Depreciation and Amortization (Including Information on Listed Property)

Department of the Treasury
Internal Revenue Service (99)

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

Attachment
Sequence No **67**

Name(s) shown on return NATIONAL ORGANIZATION FOR RARE DISC	Business or activity to which this form relates 990	Identifying number 13-3223946
-----------------------------------------------------------------------	---------------------------------------------------------------	-----------------------------------------

Part I Election To Expense Certain Property Under Section 179

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

1 Maximum amount. See the instructions for a higher limit for certain businesses	1	250,000
2 Total cost of section 179 property placed in service (see instructions).	2	188,578
3 Threshold cost of section 179 property before reduction in limitation (see instructions)	3	800,000
4 Reduction in limitation. Subtract line 3 from line 2. If zero or less, enter -0-	4	0
5 Dollar limitation for tax year. Subtract line 4 from line 1. If zero or less, enter -0-. If married filing separately, see instructions	5	250,000
6 (a) Description of property (b) Cost (business use only) (c) Elected cost		
7 Listed property. Enter the amount from line 29	7	
8 Total elected cost of section 179 property. Add amounts in column (c), lines 6 and 7	8	0
9 Tentative deduction. Enter the smaller of line 5 or line 8	9	0
10 Carryover of disallowed deduction from line 13 of your 2008 Form 4562.	10	
11 Business income limitation. Enter the smaller of business income (not less than zero) or line 5 (see instructions)	11	
12 Section 179 expense deduction. Add lines 9 and 10, but do not enter more than line 11	12	0
13 Carryover of disallowed deduction to 2010. Add lines 9 and 10, less line 12 ▶	13	0

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

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

14 Special depreciation allowance for qualified property (other than listed property) placed in service during the tax year (see instructions)	14	
15 Property subject to section 168(f)(1) election	15	
16 Other depreciation (including ACRS)	16	17,449

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

Section A

17 MACRS deductions for assets placed in service in tax years beginning before 2009	17	29,179
18 If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here <input type="checkbox"/>	18	

Section B - Assets Placed in Service During 2009 Tax Year Using the General Depreciation System

(a) Classification of property	(b) Month and year placed in service	(c) Basis for depreciation (business/investment)	(d) Recovery period	(e) Convention	(f) Method	(g) Depreciation deduction
19 a 3-year property						
b 5-year property		141,064	5	FM	S/L	16,765
c 7-year property						
d 10-year property		47,514	10	FM	S/L	1,184
e 15-year property						
f 20-year property						
g 25-year property			25 yrs.		S/L	
h Residential rental property			27.5 yrs.	MM	S/L	
i Nonresidential real property			27.5 yrs.	MM	S/L	
			39 yrs.	MM	S/L	

Section C - Assets Placed in Service During 2009 Tax Year Using the Alternative Depreciation System

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

Part IV Summary (See instructions.)

21 Listed property. Enter amount from line 28	21	
22 Total. Add amounts from line 12, lines 14 through 17, lines 19 and 20 in column (g), and line 21. Enter here and on the appropriate lines of your return. Partnerships and S corporations - see instructions	22	64,577
23 For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs	23	

For Paperwork Reduction Act Notice, see separate instructions.

Application for Extension of Time To File an Exempt Organization Return

▶ **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
 - 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 NATIONAL ORGANIZATION FOR RARE DISORDERS INC.	Employer identification number 13-3223946
File by the due date for filing your return. See instructions	Number, street, and room or suite no. If a P.O. box, see instructions. 55 KENOSIA AVENUE	
	City, town or post office, state, and ZIP code. For a foreign address, see instructions. DANBURY CT 06813-1968	

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

- | | | |
|----------------------------------------------|-------------------------------------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> Form 990 | <input type="checkbox"/> Form 990-T (corporation) | <input type="checkbox"/> Form 4720 |
| <input type="checkbox"/> Form 990-BL | <input type="checkbox"/> Form 990-T (sec. 401(a) or 408(a) trust) | <input type="checkbox"/> Form 5227 |
| <input type="checkbox"/> Form 990-EZ | <input type="checkbox"/> Form 990-T (trust other than above) | <input type="checkbox"/> Form 6069 |
| <input type="checkbox"/> Form 990-PF | <input type="checkbox"/> Form 1041-A | <input type="checkbox"/> Form 8870 |

• The books are in the care of ▶ **PETER L. SALTONSTALL 55 KENOSIA AVENUE DANBURY CT 06813**

Telephone No. ▶ **203-744-0100** FAX No. ▶ _____

- If the organization does not have an office or place of business in the United States, check this box
- If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) _____. If this is for the whole group, check this box . If it is for part of the group, check this box and attach a list with the names and EINs of all members the extension will cover.

1 I request an automatic 3-month (6 months for a corporation required to file Form 990-T) extension of time until 8/15/2010, to file the exempt organization return for the organization named above. The extension is for the organization's return for:
 ▶ calendar year 2009 or
 ▶ tax year beginning _____, and ending _____

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

3 a 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	\$ 0

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