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Form 990  Department of the Treasury Internal Revenue Service	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 2011 Open to Public Inspection
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A For the 2011 calendar year, or tax year beginning 01-01-2011 and ending 12-31-2011		
B Check if applicable ☐ Address change ☐ Name change ☐ Initial return ☐ Terminated ☐ Amended return ☐ Application pending	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 068131968	D Employer identification number 13-3223946
		E Telephone number (203) 744-0100
		G Gross receipts \$ 11,025,713
	F Name and address of principal officer PETER L SALTONSTALL 55 KENOSIA AVENUE DANBURY,CT 068131968	H(a) Is this a group return for affiliates? ☐ Yes ☒ No H(b) Are all affiliates included? ☐ Yes ☐ No If "No," attach a list (see instructions) H(c) Group exemption number ▶
	I Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () ◀ (Insert no) ☐ 4947(a)(1) or ☐ 527	
J Website: ▶ WWW.RAREDISEASES.ORG		
K Form of organization ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶		L Year of formation 1983
M State of legal domicile NY		

Part I		Summary	
Activities & Governance	1 Briefly describe the organization's mission or most significant activities IMPROVE IDENTIFICATION, TREATMENTS, AND CURE OF RARE DISEASES THROUGH PROGRAMS OF EDUCATION, ADVOCACY, RESEARCH AND SERVICE		
	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	17
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	17
	5 Total number of individuals employed in calendar year 2011 (Part V, line 2a)	5	58
	6 Total number of volunteers (estimate if necessary)	6	
	7a	0	
	7b		
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9 Program service revenue (Part VIII, line 2g)	11,456,179	9,634,015
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	1,546,470	1,296,642
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	149,312	85,651
	12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	72,776	9,405
		13,224,737	11,025,713
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)	8,953,825	8,784,207
	14 Benefits paid to or for members (Part IX, column (A), line 4)		0
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	2,684,749	2,626,834
	16a Professional fundraising fees (Part IX, column (A), line 11e)		0
	b Total fundraising expenses (Part IX, column (D), line 25) ☒ 322,574		
	17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	1,404,194	1,595,339
	18 Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	13,042,768	13,006,380
	19 Revenue less expenses Subtract line 18 from line 12	181,969	-1,980,667
Net Assets or Fund Balances		Beginning of Current Year	End of Year
	20 Total assets (Part X, line 16)	16,600,875	14,450,108
	21 Total liabilities (Part X, line 26)	1,628,439	2,309,489
	22 Net assets or fund balances Subtract line 21 from line 20	14,972,436	12,140,619

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	2012-08-01 Date	
		PETER SALTONSTALL PRESIDENT Type or print name and title		
Paid Preparer's Use Only	Preparer's signature 	CHRISTOPHER B CONLEY	Date 2012-08-01	Check if self-employed ☐
	Firm's name (or yours if self-employed), address, and ZIP + 4 	GUILMARTIN DIPIRO & SOKOLOWSKI LLC 213 COURT ST SUITE 703 MIDDLETOWN, CT 064573367		
		EIN ▶	Phone no ▶ (860) 347-5689	
May the IRS discuss this return with the preparer shown above? (see instructions) ☐ Yes ☐ No				

Part III

Statement of Program Service Accomplishments

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

1

Briefly describe the organization’s mission

IMPROVE IDENTIFICATION, TREATMENTS, 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 organization’s program service accomplishments for each of its three largest program services, as measured by expenses Section 501(c)(3) and 501(c)(4) organizations 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 \$ 9,294,883 including grants of \$ 8,514,207) (Revenue \$ 1,185,435)

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 \$ 1,758,596 including grants of \$) (Revenue \$ 111,207)

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

4c

(Code) (Expenses \$ 493,656 including grants of \$ 270,000) (Revenue \$)

ADVOCACY SERVES AS THE LIASON BETWEEN THE RARE DISEASE COMMUNITY AND THE NATIONAL INSTITUTIONS THAT HAVE A DIRECT IMPACT ON THEIR HEALTH

(Code) (Expenses \$ 550,756 including grants of \$) (Revenue \$)

TECHNICAL ASSISTANCE PROVIDE ASSISTANCE TO VOLUNTARY HEALTH AGENCIES AND SUPPORT GROUPS TO IMPROVE THEIR EFFECTIVENESS, COMPLIANCE WITH NON-PROFIT STANDARDS AND PROGRAM DEVELOPMENT

4d

Other program services (Describe in Schedule O)

(Expenses \$ 550,756 including grants of \$) (Revenue \$)

4e

Total program service expenses

\$ 12,097,891

Form 990 (2011)

Part IV Checklist of Required Schedules

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A.	Yes	
2	Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	Yes	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I.		No
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II.	Yes	
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III.		No
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I.		No
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? If "Yes," complete Schedule D, Part II.		No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III.		No
9	Did the organization report an amount in Part X, line 21, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV.		No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V.		No
11	If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.	Yes	
b	Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII.		No
c	Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII.		No
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX.		No
e	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.		No
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X.		No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI, XII, and XIII.	Yes	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI, XII, and XIII is optional.		No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E.		No
14a	Did the organization maintain an office, employees, or agents outside of the United States?		No
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Part I.		No
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the U S? If "Yes," complete Schedule F, Part II and IV.	Yes	
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 U S? If "Yes," complete Schedule F, Part III and IV.		No
17	Did the organization report a total of more than \$15,000, of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I.		No
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II.	Yes	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III.		No
20a	Did the organization operate one or more hospitals? If "Yes," complete Schedule H.		No
b	If "Yes" to line 20a, did the organization attach its audited financial statement to this return? Note. All Form 990 filers that operated one or more hospitals must attach audited financial statements.		
20b			

Part IV

Checklist of Required Schedules (continued)

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	Yes	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, questions 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	Yes	
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 questions 24b–24d and complete Schedule K. If "No," go to line 25</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, 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		No
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		No
28	Was the organization a party to a business transaction with one of the following parties? (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34		No
35a	Is any related organization a controlled entity of the filing organization within the meaning of section 512(b)(13)?	35a		No
b	Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V		Statements Regarding Other IRS Filings and Tax Compliance		
Check if Schedule O contains a response to any question in this Part V ☐				
			Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable. .	1a	3	
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	1b	0	
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes	
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. .	2a	58	
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 (see instructions).	2b	Yes	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		No
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 or securities account)?	4a		No
b	If "Yes," enter the name of the foreign country: _____ See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		No
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	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		No
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		
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		
d	If "Yes," indicate the number of Forms 8282 filed during the year.	7d		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	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		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.			
a	Is the organization licensed to issue qualified health plans in more than one state? Note. All 501(c)(29) organizations must list in Schedule O each state in which they are licensed to issue qualified health plans, the amount of reserves required by each state, and the amount of reserves the organization allocated to each state.	13a		
b	Enter the aggregate amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.	13b		
c	Enter the aggregate amount of reserves on hand.	13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		No
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.	14b		

Part VI

Governance, Management, and Disclosure For each “Yes” response to lines 2 through 7b below, and for a “No” response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.
Check if Schedule O contains a response to any question in this Part VI ☒

Section A. Governing Body and Management			Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	1a	17	
	1b	17		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2		No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?	3		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		No
5	Did the organization become aware during the year of a significant diversion of the organization’s assets?	5		No
6	Did the organization have members or stockholders?	6		No
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	7a		No
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
8a	The governing body?	8a	Yes	
8b	Each committee with authority to act on behalf of the governing body?	8b	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization’s mailing address? If “Yes,” provide the names and addresses in Schedule O	9		No

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a		No
10b	If “Yes,” did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization’s exempt purposes?	10b		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	Yes	
11b	Describe in Schedule O the process, if any, used by the organization to review the Form 990			
12a	Did the organization have a written conflict of interest policy? <i>If “No,” go to line 13</i>	12a	Yes	
12b	Were officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b		No
12c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If “Yes,” describe in Schedule O how this was done	12c		No
13	Did the organization have a written whistleblower policy?	13	Yes	
14	Did the organization have a written document retention and destruction policy?	14	Yes	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
15a	The organization’s CEO, Executive Director, or top management official	15a	Yes	
15b	Other officers or key employees of the organization	15b	Yes	
	If “Yes,” to line 15a or 15b, describe the process in Schedule O (see instructions)			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	16a		No
16b	If “Yes,” did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization’s exempt status with respect to such arrangements?	16b		

Section C. Disclosure	
17	List the States with which a copy of this Form 990 is required to be filed ▶ CT , NY , AK , AL , AZ , CA , CO , DC , FL , GA , IL , IN , KS , KY , MA , MD , ME , MI , MN , MS , NC , NH , NJ , NM , NV , OH , OK , OR , PA , RI , SC , TN , UT , VA , WA , WI , WV
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c) (3)s only) available for public inspection. Indicate how you made these available. Check all that apply. ☒ Own website ☐ Another’s website ☒ Upon request
19	Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public. See Additional Data Table.
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization ▶ PETER SALTONSTALL 55 KENOSIA AVENUE DANBURY, CT 06813 (203) 744-0100

Part VII

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation, and **current** key employees Enter -0- in columns (D), (E), and (F) if no compensation was paid
- List all of the organization's **current** key employees, if any See instructions for definition of "key employee "
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations
- List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations

List persons in the following order individual trustees or directors, institutional trustees, officers, key employees, highest compensated employees, and former such persons

Check this box if neither the organization nor any related organizations compensated any current or former officer, director, or trustee

(A) Name and Title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) E MICHAEL D SCOTT CHAIR	2 00	X		X				0	0	0
(2) CAROLYN ASBURY VICE CHAIR	2 00	X		X				0	0	0
(3) JOSEPHINE GRIMA PHD SECRETARY	2 00	X		X				0	0	0
(4) STEPHEN BAJARDI TREASURER	2 00	X		X				0	0	0
(5) ESTELLE BENSON DIRECTOR	2 00	X						0	0	0
(6) JIM BROATCH DIRECTOR	2 00	X						0	0	0
(7) BRENDA DUFFY DIRECTOR	2 00	X						0	0	0
(8) PAT FURLONG DIRECTOR	2 00	X						0	0	0
(9) MIRA GEFFNER DIRECTOR	2 00	X						0	0	0
(10) NANCY HARRIS DIRECTOR	2 00	X						0	0	0
(11) MARYBETH KRUMMENACKER DIRECTOR	2 00	X						0	0	0
(12) VICKI MCARRELL DIRECTOR	2 00	X						0	0	0
(13) FRANK J SASINOWSKI DIRECTOR	2 00	X						0	0	0
(14) SHELDON M SCHUSTER DIRECTOR	2 00	X						0	0	0
(15) JUDITH UNGAR DIRECTOR	2 00	X						0	0	0
(16) CHARLENE WALDMAN DIRECTOR	2 00	X						0	0	0
(17) WENDY WHITE DIRECTOR	2 00	X						0	0	0

Part VII

1b	Sub-Total			
c	Total from continuation sheets to Part VII, Section A			
d	Total (add lines 1b and 1c)	414,691		31,443

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

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

Section B. Independent Contractors

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

(A) Name and business address	(B) Description of services	(C) Compensation
PCI STRATEGIES 22 BATES ROAD MASHPEE, MA 02649	HEALTHCARE/IT	141,465
2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶1		

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	46,134				
	b	Membership dues	1b	49,270				
	c	Fundraising events	1c	637,050				
	d	Related organizations	1d					
	e	Government grants (contributions)	1e					
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	8,901,561				
	g	Noncash contributions included in lines 1a-1f \$ _____						
	h	Total. Add lines 1a-1f						9,634,015
Program Service Revenue			Business Code					
	2a	INDIGENT CARE DRUG COPAY	624100	1,185,435	1,185,435			
	b	LITERATURE/MATERIALS/RESEARCH	541700	111,207	111,207			
	c							
	d							
	e							
	f	All other program service revenue						
	g	Total. Add lines 2a-2f			1,296,642			
Other Revenue	3	Investment income (including dividends, interest and other similar amounts)		85,651			85,651	
	4	Income from investment of tax-exempt bond proceeds . .						
	5	Royalties						
	6a	(i) Real		(ii) Personal				
	b	Less rental expenses						
	c	Rental income or (loss)						
	d	Net rental income or (loss)						
	7a	(i) Securities		(ii) Other				
	b	Less cost or other basis and sales expenses						
	c	Gain or (loss)						
	d	Net gain or (loss)						
	8a	Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c) See Part IV, line 18		a				
		b	Less direct expenses					
	c	Net income or (loss) from fundraising events . .						
	9a	Gross income from gaming activities See Part IV, line 19		a				
		b	Less direct expenses					
	c	Net income or (loss) from gaming activities . .						
10a	Gross sales of inventory, less returns and allowances		a					
	b	Less cost of goods sold						b
c	Net income or (loss) from sales of inventory . .							
Miscellaneous Revenue		Business Code						
11a	INSURANCE PROCEEDS			9,194			9,194	
b	MISCELLANEOUS INCOME			211			211	
c								
d	All other revenue							
e	Total. Add lines 11a-11d			9,405				
12	Total revenue. See Instructions			11,025,713	1,296,642		95,056	

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States See Part IV, line 21	110,000	110,000		
2	Grants and other assistance to individuals in the United States See Part IV, line 22	8,514,207	8,514,207		
3	Grants and other assistance to governments, organizations, and individuals outside the United States See Part IV, lines 15 and 16	160,000	160,000		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	273,515	199,666	49,233	24,616
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	1,868,878	1,373,331	324,083	171,464
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)	85,388	66,603	11,100	7,685
9	Other employee benefits	229,150	177,272	44,713	7,165
10	Payroll taxes	169,903	129,671	32,066	8,166
11	Fees for services (non-employees)				
a	Management				
b	Legal	79,916	79,916		
c	Accounting	12,150	12,150		
d	Lobbying				
e	Professional fundraising See Part IV, line 17				
f	Investment management fees				
g	Other	192,724	143,877	4,869	43,978
12	Advertising and promotion	110,705	107,192		3,513
13	Office expenses	76,493	64,599	9,602	2,292
14	Information technology	69,680	69,680		
15	Royalties				
16	Occupancy	149,668	117,799	24,307	7,562
17	Travel	136,425	126,628	4,320	5,477
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	289,237	289,237		
20	Interest	43,602	36,190	6,976	436
21	Payments to affiliates				
22	Depreciation, depletion, and amortization	126,443	104,948	20,231	1,264
23	Insurance	30,072	23,712	5,652	708
24	Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24f If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O)				
a	DUES/SUBSCRIPTIONS/REG	52,039	37,121	2,480	12,438
b	TELEPHONE	47,655	30,130	15,210	2,315
c	TEMPORARY LABOR	32,171	16,402		15,769
d	REPAIRS & MAINTENANCE	27,974	14,218	13,476	280
e					
f	All other expenses	118,385	93,342	17,597	7,446
25	Total functional expenses. Add lines 1 through 24f	13,006,380	12,097,891	585,915	322,574
26	Joint costs. Check here if following SOP 98-2 (ASC 958-720) 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)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			250	1	755,219
	2	Savings and temporary cash investments			14,185,928	2	11,283,986
	3	Pledges and grants receivable, net			97,800	3	
	4	Accounts receivable, net				4	339,626
	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			87,336	9	83,883
	10a	Land, buildings, and equipment, cost or other basis. Complete Part VI of Schedule D	10a	2,522,072	1,705,595	10c	1,638,482
	b	Less: accumulated depreciation	10b	883,590			
	11	Investments—publicly traded securities			518,787	11	343,733
	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			5,179	15	5,179
	16	Total assets. Add lines 1 through 15 (must equal line 34)			16,600,875	16	14,450,108
Liabilities	17	Accounts payable and accrued expenses			121,839	17	963,657
	18	Grants payable			518,491	18	574,740
	19	Deferred revenue			211,370	19	35,000
	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			776,739	23	736,092
	24	Unsecured notes and loans payable to unrelated third parties				24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D				25	
	26	Total liabilities. Add lines 17 through 25			1,628,439	26	2,309,489
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			6,074,123	27	5,252,910
	28	Temporarily restricted net assets			8,898,313	28	6,887,709
	29	Permanently restricted net assets				29	
	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			14,972,436	33	12,140,619
	34	Total liabilities and net assets/fund balances			16,600,875	34	14,450,108

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	11,025,713
2	Total expenses (must equal Part IX, column (A), line 25)	2	13,006,380
3	Revenue less expenses Subtract line 2 from line 1	3	-1,980,667
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	14,972,436
5	Other changes in net assets or fund balances (explain in Schedule O)	5	-851,150
6	Net assets or fund balances at end of year Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	12,140,619

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990 ☐ Cash ☒ Accrual ☐ Other If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		No
b	Were the organization's financial statements audited by an independent accountant?	Yes	
c	If "Yes," to 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	Yes	
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 separate basis, consolidated basis, or both ☐ Separate basis ☒ Consolidated basis ☐ Both consolidated and separated 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?		No
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		

SCHEDULE A

(Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

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

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC	Employer identification number 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 **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 Se**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 the supported organization?

(ii)

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

(iii)

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

h

☐

Provide the following information about the supported organization(s)

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

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

Part II

Support Schedule for Organizations Described in IRC 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	11,438,927	10,475,348	12,041,663	11,456,178	9,634,015	55,046,131
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	11,438,927	10,475,348	12,041,663	11,456,178	9,634,015	55,046,131
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						55,046,131

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
7 Amounts from line 4	11,438,927	10,475,348	12,041,663	11,456,178	9,634,015	55,046,131
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	617,658	524,158	255,056	138,292	85,651	1,620,815
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income (Explain in Part IV) Do not include gain or loss from the sale of capital assets					9,405	9,405
11 Total support (Add lines 7 through 10)						56,676,351

12 Gross receipts from related activities, etc (See instructions)

1297,111,461

13 First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here

Section C. Computation of Public Support Percentage

14 Public Support Percentage for 2011 (line 6 column (f) divided by line 11 column (f))	14	97 120 %
15 Public Support Percentage for 2010 Schedule A, Part II, line 14	15	97 140 %

16a 33 1/3% support test—2011. 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—2010. If the organization did not check the 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—2011. 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—2010. If the organization did not check a box on line 13, 16a, 16b, or 17a and line 15 is 10% or more, and if the organization meets the "facts and circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

18 Private Foundation If the organization did not check a box on line 13, 16a, 16b, 17a or 17b, check this box and see instructions

Part IIIPart III

Support Schedule for Organizations Described in IRC 509(a)(2)
(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support						
Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(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) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(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 501(c)(3) organization, check this box and stop here						

Section C. Computation of Public Support Percentage		
15 Public Support Percentage for 2011 (line 8 column (f) divided by line 13 column (f))	15	
16 Public support percentage from 2010 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2011 (line 10c column (f) divided by line 13 column (f))	17	
18 Investment income percentage from 2010 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2011. 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—2010. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization		
20 Private Foundation If the organization did not check a box on line 14, 19a or 19b, check this box and see instructions		

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

Facts And Circumstances Test

Explanation

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

▶ Complete if the organization is described below.
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No 1545-0047

2011

Open to Public Inspection

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

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

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

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

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

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

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC	Employer identification number 13-3223946
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Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

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

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

Part II-A

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

- A

Check

☐

if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures)
- B

Check

☐

if the filing organization checked box A and "limited control" provisions apply

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing Organization's Totals	(b) Affiliated Group Totals												
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)															
b Total lobbying expenditures to influence a legislative body (direct lobbying)															
c Total lobbying expenditures (add lines 1a and 1b)															
d Other exempt purpose expenditures															
e Total exempt purpose expenditures (add lines 1c and 1d)															
f Lobbying nontaxable amount Enter the amount from the following table in both columns															
<table><tr><td>If the amount on line 1e, column (a) or (b) is:</td><td>The lobbying nontaxable amount is:</td></tr><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></table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000	Over \$17,000,000	\$1,000,000		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000														
Over \$17,000,000	\$1,000,000														
g Grassroots nontaxable amount (enter 25% of line 1f)															
h Subtract line 1g from line 1a If zero or less, enter -0-															
i Subtract line 1f from line 1c If zero or less, enter -0-															
j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?		☐ 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) Total
2a Lobbying non-taxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots non-taxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Part II-B

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

		(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?		No	
	b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	Yes		
	c Media advertisements?		No	
	d Mailings to members, legislators, or the public?		No	
	e Publications, or published or broadcast statements?		No	
	f Grants to other organizations for lobbying purposes?		No	
	g Direct contact with legislators, their staffs, government officials, or a legislative body?		No	
	h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		No	
	i Other activities? If "Yes," describe in Part IV	Yes		16,008
	j Total lines 1c through 1i			16,008
	2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		No	
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?			No	

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	No
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	No
3	Did the organization agree to carryover lobbying and political expenditures from the prior year?	3	No

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

Part IV

Supplemental Information

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.

Identifier	Return Reference	Explanation
	SCHEDULE C, PART II-B, LINE 1	THE NATIONAL ORGANIZATION FOR RARE DISORDERS HAS AN OFFICE IN WASHINGTON, DC WHERE AN EMPLOYEE USES A SMALL PORTION OF THEIR TIME TO STAY IN TOUCH WITH LEGISLATION AFFECTING HEALTH AND DISEASES. THIS INFORMATION WILL BE POSTED ON OUR WEBSITE WHICH WILL, AT TIMES, HAVE PETITIONS FOR INDIVIDUALS TO SIGN ONLINE.

SCHEDULE D
(Form 990)

Supplemental Financial Statements

Department of the Treasury
Internal Revenue Service

OMB No 1545-0047

2011

Open to Public Inspection

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

Attach to Form 990. See separate instructions.

Name of the organization
NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Employer identification number
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?	
	☐ Yes☒ No	
6	Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may 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 importantly land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2

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

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

3

Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the taxable 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 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

▶ \$

For Privacy Act and Paperwork Reduction Act Notice, see the Intructions for Form 990

Cat No 52283D

Schedule D (Form 990) 2011

Part III

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

3

Using the organization's 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
1c	
1d	
1e	
1f	

2a

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

☐ Yes☒ No

b

If "Yes," explain the arrangement in Part 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				
c	Investment earnings or losses				
d	Grants or scholarships				
e	Other expenditures for facilities and programs				
f	Administrative expenses				
g	End of year balance				

2

Provide the estimated percentage of the 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

3a(i)

☐ Yes☐ No

(ii)

related organizations

3a(ii)

☐ Yes☐ No

b

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

3b

☐ Yes☐ No

4

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

Part VI

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land		360,600		360,600
b Buildings		906,200	157,854	748,346
c Leasehold improvements		11,910	6,352	5,558
d Equipment		1,243,362	719,384	523,978
e Other				
Total. Add lines 1a-1e (Column (d) should equal Form 990, Part X, column (B), line 10(c).) ▶				1,638,482

Part XI

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

1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	11,025,713
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	13,006,380
3	Excess or (deficit) for the year Subtract line 2 from line 1	3	-1,980,667
4	Net unrealized gains (losses) on investments	4	-12,031
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	-839,119
8	Other (Describe in Part XIV)	8	
9	Total adjustments (net) Add lines 4 - 8	9	-851,150
10	Excess or (deficit) for the year per financial statements Combine lines 3 and 9	10	-2,831,817

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	19,657,699
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	-12,031
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV)	2d	8,644,017
e	Add lines 2a through 2d	2e	8,631,986
3	Subtract line 2e from line 1	3	11,025,713
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total Revenue Add lines 3 and 4c. (This should equal Form 990, Part I, line 12)	5	11,025,713

Part XIII

Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

1	Total expenses and losses per audited financial statements	1	22,489,516
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	839,119
c	Other losses	2c	
d	Other (Describe in Part XIV)	2d	8,644,017
e	Add lines 2a through 2d	2e	9,483,136
3	Subtract line 2e from line 1	3	13,006,380
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total expenses Add lines 3 and 4c. (This should equal Form 990, Part I, line 18)	5	13,006,380

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, 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.

Identifier	Return Reference	Explanation
RECONCILIATION OF CHANGES - OTHER	SCHEDULE D, PAGE 4, PART XI, LINE 8	NET ASSETS RELEASED FROM RESTRICTION 8,644,017 NET ASSETS RELEASED FROM RESTRICTION -8,644,017
REVENUE AMOUNTS INCLUDED IN FINANCIALS - OTHER	SCHEDULE D, PAGE 4, PART XII, LINE 2D	NET ASSETS RELEASED FROM RESTRICTION 8,644,017
EXPENSE AMOUNTS INCLUDED IN FINANCIALS - OTHER	SCHEDULE D, PAGE 4, PART XIII, LINE 2D	NET ASSETS RELEASED FROM RESTRICTION 8,644,017

Part II

Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Check this box if no one recipient received more than \$5,000 ☐

Use Part V if additional space is needed.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			EUROPE	CORTICOBASAL DEGEN	30,000	CHECK			
			EUROPE	SYSTEMIC SCLEROSIS	30,000	CHECK			
			EUROPE	PMP	50,000	CHECK			
			EUROPE	PMP	50,000	CHECK			

2

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

3

Enter total number of other organizations or entities ☐

Part III

[illegible]

Part IV Foreign Forms

- 1

Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926 (see instructions for Form 926)*

☐ Yes ☐ No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If " Yes," the organization may be required to file Form 3520 and/or Form 3520-A. (see instructions for Forms 3520 and 3520-A)*

☐ Yes ☐ No
- 3

Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with respect to Certain Foreign Corporations. (see instructions for Form 5471)*

☐ Yes ☐ No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see instructions for Form 8621)*

☐ Yes ☐ No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with respect to Certain Foreign Partnerships. (see instructions for Form 8865)*

☐ Yes ☐ No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report (see instructions for Form 5713).*

☐ Yes ☐ No

Supplemental Information

Complete this part to provide the information (see instructions) required in Part I, line 2, and any additional information.

[illegible]

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding
Fundraising or Gaming Activities

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

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Employer identification number

13-3223946

Part I Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17.

1

Indicate whether the organization raised funds through any of the following activities. Check all that apply.

a

☐ Mail solicitations

b

☐ Internet and e-mail solicitations

c

☐ Phone solicitations

d

☐ In-person solicitations

e

☐ Solicitation of non-government grants

f

☐ Solicitation of government grants

g

☐ Special fundraising events

2a

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. Form 990-EZ filers are not required to complete this table.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
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.

For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990. Cat No 50083H Schedule G (Form 990 or 990-EZ) 2011

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
		990PTVIII1C (event type)	(event type)	(total number)	(Add col (a) through col (c))
Revenue	1	Gross receipts	637,050		637,050
	2	Less Charitable contributions	637,050		637,050
	3	Gross income (line 1 minus line 2)			
Direct Expenses	4	Cash prizes			
	5	Non-cash prizes			
	6	Rent/facility costs			
	7	Food and beverages			
	8	Entertainment			
	9	Other direct expenses			
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶			
	11	Net income summary Combine lines 3 and 10 in column (d). ▶			

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			
	2	Cash prizes			
Direct Expenses	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	7	Direct expense summary Add lines 2 through 5 in column (d) ▶			
	8	Net gaming income summary Combine lines 1 and 7 in column (d) ▶			

9 Enter the state(s) in which the organization operates gaming activities _____

a Is the organization licensed to operate gaming activities in each of these states? ☐ Yes ☐ No

b If "No," Explain _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? ☐ Yes ☐ No

b If "Yes," Explain _____

- 11

Does the organization operate gaming activities with nonmembers?

Yes

No
- 12

Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?

Yes

No

13

Indicate the percentage of gaming activity operated in

a	The organization's facility	13a
b	An outside facility	13b

14

Provide the name and address of the person who prepares the organization's gaming/special events books and records

Name

Address

15a

Does the organization have a contract with a third party from whom the organization receives gaming revenue?

Yes

No

b

If "Yes," enter the amount of gaming revenue received by the organization \$ and the amount of gaming revenue retained by the third party \$

c

If "Yes," enter name and address

Name

Address

16

Gaming manager information

Name

Gaming manager compensation

\$

Description of services provided

Director/officer

Employee

Independent contractor

17

Mandatory distributions

a

Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?

Yes

No

b

Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year \$

Part IV

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

Identifier	ReturnReference	Explanation
------------	-----------------	-------------

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

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

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

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Employer identification number
13-3223946

Part I

General Information on Grants and Assistance

1

Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☒ Yes ☐ No

2

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

Part II

Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Use Part IV and Schedule I-1 (Form 990) if additional space is needed ☐

(a) Name and address of organization or government	(b) EIN	(c) IRC Code section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
(1) MD ANDERSON CANCER CENTER DIANA BELL MDMD ANDERSON CANCER CENTER HOUSTON,TX 77030	74-6000203	501	30,000				ADENOID CYSTIC CARC
(2) UNIVERSITY OF CALIFORNIA ANDREW M LOWRY MD 9500 GILMAN DR LA JOLLA,CA 92093	94-6036493	GOV	50,000				PMP
(3) MONELL CHEMICAL SENSES CENTER DANIELLE REED PHD/GEORGE PRETI PHD UNIVERSITY CITY SCIENCE CENTER PHILADELPHIA,PA 19014	23-2020897	501	30,000				TRIMETHYLAMINURIA

2

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

3

Enter total number of other organizations listed in the line 1 table

Part III

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Use 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
(1) INSURANCE/DRUGS/MEDICAL	2421	8,514,207			

Part IV

Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information.

Identifier	Return Reference	Explanation
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Schedule J
(Form 990)

Compensation Information

OMB No 1545-0047

2011

Open to Public Inspection

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

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

▶ Attach to Form 990. ▶ See separate instructions.

Name of the organization

NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Employer identification number

13-3223946

Part I

Questions Regarding Compensation

		Yes	No
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 idemnification 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 in line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all the expenses described above? If "No," complete Part III to explain	1b	
2	Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all officers, directors, trustees, and the CEO/Executive Director, regarding the items checked in line 1a?	2	
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?	4a	No
b	Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b	No
c	Participate in, or receive payment from, an equity-based compensation arrangement?	4c	No
	If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III		
	Only 501(c)(3) and 501(c)(4) organizations only must complete lines 5-9.		
5	For persons listed in form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of		
a	The organization?	5a	No
b	Any related organization?	5b	No
	If "Yes," to line 5a or 5b, describe in Part III		
6	For persons listed in form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of		
a	The organization?	6a	No
b	Any related organization?	6b	No
	If "Yes," to line 6a or 6b, describe in Part III		
7	For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III	7	No
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	8	No
9	If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53 4958-6(c)?	9	

For each individual whose compensation must be reported in Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions on row (ii). Do not list any individuals that are not listed on Form 990, Part VII.

[illegible]

Part III **Supplemental Information**

Complete this part to provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 4c, 5a, 5b, 6a, 6b, 7, and 8. Also complete this part for any additional information.

Identifier	Return Reference	Explanation
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SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

**Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.**
► Attach to Form 990 or 990-EZ.

OMB No 1545-0047

2011

**Open to Public
Inspection**

Name of the organization
NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Employer identification number

13-3223946

Identifier	Return Reference	Explanation
ALL OTHER ACCOMPLISHMENT DESCRIPTION	FORM 990, PAGE 2, PART III, LINE 4D	TECHNICAL ASSISTANCE PROVIDE ASSISTANCE TO VOLUNTARY HEALTH AGENCIES AND SUPPORT GROUPS TO IMPROVE THEIR EFFECTIVENESS, COMPLIANCE WITH NON-PROFIT STANDARDS AND PROGRAM DEVELOPMENT
ORGANIZATION'S PROCESS USED TO REVIEW FORM 990	FORM 990, PAGE 6, PART VI, LINE 11B	REVIEWED BY CFO, CEO, TREASURER, FINANCE COMMITTEE, EXECUTIVE COMMITTEE AND CHAIRPERSON OF THE AUDIT COMMITTEE PRIOR TO FILING
COMPENSATION PROCESS FOR TOP OFFICIAL	FORM 990, PAGE 6, PART VI, LINE 15A	THE BOARD OF DIRECTORS REVIEWS EXTERNAL MARKET SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS FOR DECISIONS ON THE EXECUTIVE DIRECTOR COMPENSATION THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION
COMPENSATION PROCESS FOR OFFICERS	FORM 990, PAGE 6, PART VI, LINE 15B	THE BOARD OF DIRECTORS REVIEWS EXTERNAL MARKET SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS FOR DECISIONS ON THE EXECUTIVE DIRECTOR COMPENSATION THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION
STATES WHERE COPY OF RETURN IS FILED	FORM 990, PAGE 6, PART VI, LINE 17	KENTUCKY, MASSACHUSETTS, MARYLAND, MAINE, MICHIGAN, MINNESOTA, MISSISSIPPI, NORTH CAROLINA, NEW HAMPSHIRE, NEW JERSEY, NEW MEXICO, NEVADA, OHIO, OKLAHOMA, OREGON, PENNSYLVANIA, RHODE ISLAND, SOUTH CAROLINA, TENNESSEE, UTAH, VIRGINIA, WASHINGTON, WISCONSIN, WEST VIRGINIA
GOVERNING DOCUMENTS DISCLOSURE EXPLANATION	FORM 990, PAGE 6, PART VI, LINE 19	GOVERNING DOCUMENTS ARE MADE AVAILABLE UPON REQUEST WITHIN A REASONABLE AMOUNT OF TIME
OTHER CHANGES IN NET ASSETS EXPLANATION	FORM 990, PART XI, LINE 5	THE ADJUSTMENT TO NET ASSETS IS A PRIOR PERIOD AUDIT ADJUSTMENT

Additional Data

Software ID:
Software Version:
EIN: 13-3223946
Name: NATIONAL ORGANIZATION FOR RARE
DISORDERS INC

Form 990, Special Condition Description:

Special Condition Description

Form 990, Part III - 4 Program Service Accomplishments (See the Instructions)

4d. Other program services
(Code) (Expenses \$ 550,756 including grants of \$) (Revenue \$) TECHNICAL ASSISTANCE PROVIDE ASSISTANCE TO VOLUNTARY HEALTH AGENCIES AND SUPPORT GROUPS TO IMPROVE THEIR EFFECTIVENESS, COMPLIANCE WITH NON-PROFIT STANDARDS AND PROGRAM DEVELOPMENT