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Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III ☐ ☒

1

Briefly describe the organization's mission

A UNIQUE FEDERATION OF VOLUNTARY HEALTH ORGANIZATIONS DEDICATED TO HELPING PEOPLE WITH RARE ORPHAN DISEASES AND ASSISTING THE ORGANIZATIONS THAT SERVE THEM NORD IS COMMITTED TO THE IDENTIFICATION, TREATMENT, AND CURE OF RARE DISORDERS 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 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 \$ 12,459,521 including grants of \$ 11,826,511) (Revenue \$ 1,565,007)

PATIENT SERVICES PROVIDES PATIENT ASSISTANCE PROGRAMS INCLUDING FREE DRUG, PREMIUM AND CO-PAY ASSISTANCE, TRAVEL AND LODGING ASSISTANCE FOR CLINICAL TRIALS, AND EXPANDED EMERGENCY AND ANCILLARY ACCESS PROGRAMS

4b

(Code) (Expenses \$ 708,174 including grants of \$) (Revenue \$)

MEMBERSHIP AND EDUCATION PROVIDES TRAINING AND MENTORING TO ASSIST RARE DISEASE PATIENT ORGANIZATIONS IN ACHIEVING THE HIGHEST POSSIBLE LEVEL OF SERVICE TO THEIR MEMBERS WHILE ADOPTING BEST PRACTICES AND ADHERING TO ACCEPTED NON-PROFIT STANDARDS ALSO, PATIENT AND FAMILY EDUCATION, HEALTH PROFESSIONAL EDUCATION, AND PUBLIC AWARENESS PROGRAMS ARE OFFERED THROUGH EXTENSIVE ONLINE, ELECTRONIC, IN-PERSON, AND IN-PRINT EDUCATIONAL RESOURCES AND PROGRAMS

4c

(Code) (Expenses \$ 620,136 including grants of \$ 255,000) (Revenue \$)

RESEARCH AND MEDICAL AND SCIENTIFIC AFFAIRS ADMINISTERS A PROGRAM OF GRANTS AND FELLOWSHIPS TO SUPPORT RESEARCH ON RARE DISEASES FUNDED BY CONTRIBUTIONS FROM THE PUBLIC, PATIENTS AND THEIR FAMILIES, AND PATIENT ORGANIZATIONS

(Code) (Expenses \$ 385,505 including grants of \$) (Revenue \$)

ADVOCACY SERVES AS THE LIASON BETWEEN THE RARE DISEASE COMMUNITY AND NATIONAL INSTITUTIONS THAT HAVE A DIRECT IMPACT ON THE HEALTH OF THE THIRTY MILLION AMERICANS LIVING WITH RARE DISEASES, INCLUDING THE U S CONGRESS, FOOD AND DRUG ADMINISTRATIONS, AND NATIONAL INSTITUTES OF HEALTH

4d

Other program services (Describe in Schedule O)

(Expenses \$ 385,505 including grants of \$) (Revenue \$)

4e

Total program service expenses ▶ 14,173,336

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 	1 Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	2 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 	3	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 	4 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 	5	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 	6	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 	7	No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III 	8	No
9 Did the organization report an amount in Part X, line 21 for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV 	9	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 	10	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. 	11a 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 	11b	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 	11c	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 	11d Yes	
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X 	11e	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 	11f Yes	
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII 	12a 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 and XII is optional 	12b	No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	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, Parts I and IV 	14b Yes	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV 	15 Yes	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV 	16	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 (see instructions) 	17	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 	18 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 	19	No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	Yes	
22	Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23	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 lines 24b through 24d and complete Schedule K. If "No," go to line 25a</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	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If so, complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	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 direct or indirect 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, Part II, III, or IV, and Part V, line 1</i>	34		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		
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 11b 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 or note to any line in this Part V

☐

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.	24	
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	0	
1c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		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.	54	
2b 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).		Yes	
3a Did the organization have unrelated business gross income of \$1,000 or more during the year?			No
3b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O.			
4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?			No
4b 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?			No
5b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			No
5c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?			
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 as charitable contributions?			No
6b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?			
7 Organizations that may receive deductible contributions under section 170(c).			
7a 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?			No
7b If "Yes," did the organization notify the donor of the value of the goods or services provided?			
7c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?			No
7d If "Yes," indicate the number of Forms 8282 filed during the year.			
7e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			No
7f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?			No
7g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?			
7h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?			
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?			
9 Sponsoring organizations maintaining donor advised funds.			
9a Did the organization make any taxable distributions under section 4966?			
9b Did the organization make a distribution to a donor, donor advisor, or related person?			
10 Section 501(c)(7) organizations. Enter			
10a Initiation fees and capital contributions included on Part VIII, line 12.			
10b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.			
11 Section 501(c)(12) organizations. Enter			
11a Gross income from members or shareholders.			
11b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).			
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?			
12b If "Yes," enter the amount of tax-exempt interest received or accrued during the year.			
13 Section 501(c)(29) qualified nonprofit health insurance issuers.			
13a Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.			
13b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.			
13c Enter the amount of reserves on hand.			
14a Did the organization receive any payments for indoor tanning services during the tax year?			No
14b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.			

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 or note to any line 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	14	
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
b	Enter the number of voting members included in line 1a, above, who are independent	14	
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
b	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		
a	The governing body?	8a	Yes
b	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	Yes
b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	10b	Yes
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
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	Yes
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?		
a	The organization's CEO, Executive Director, or top management official	15a	Yes
b	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
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	16b	

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed	CT, NY, AK, AL, AZ, CA, CO, 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, AR, HI, ND
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 ☐ Other (explain in Schedule O)	
19	Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year	
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization	PETER SALTONSTALL 1900 CROWN COLONY DRIVE 4TH FLOOR QUINCY, MA 02169 (617) 249-7300

Part VII

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

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

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

- 1a Complete this table for all persons required to be listed Report compensation for the calendar year ending with or within the organization's tax year
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation Enter -0- in columns (D), (E), and (F) if no compensation was paid

List all of the organization's **current** key employees, if any See instructions for definition of "key employee "

List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations

List all of the organization's **former** officers, key employees, 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 organization compensated any current officer, director, or trustee

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) CAROLYN ASBURY PHD RESIGNED DEC2013 VICE CHAIR	2 00	X		X				0	0	0
(2) MIRA GEFFNER RESIGNED DEC2013 DIRECTOR	2 00	X						0	0	0
(3) STEPHEN BAJARDI DIRECTOR	2 00	X						0	0	0
(4) JOSEPHINE GRIMA PHD SECRETARY	2 00	X		X				0	0	0
(5) RONALD J BARTEK CHAIR	2 00	X		X				0	0	0
(6) NANCY HARRIS DIRECTOR	2 00	X						0	0	0
(7) BRENDA DUFFY RESIGNED DEC 2013 DIRECTOR	2 00	X						0	0	0
(8) KIM HOLLANDER DIRECTOR	2 00	X						0	0	0
(9) PAT FURLONG DIRECTOR	2 00	X						0	0	0
(10) BRETT KOPELAN TREASURER	2 00	X		X				0	0	0
(11) SARAH KRUG DIRECTOR	2 00	X						0	0	0
(12) SHELDON M SCHUSTER VICE CHAIR	2 00	X		X				0	0	0
(13) MARYBETH KRUMMENACKER DIRECTOR	2 00	X						0	0	0
(14) E MICHAEL D SCOTT RESIGNED DEC2013 CHAIR	2 00	X		X				0	0	0
(15) VICKI MCCARRELL DIRECTOR	2 00	X						0	0	0
(16) MARSHALL L SUMMAR MD DIRECTOR	2 00	X						0	0	0
(17) KARI LUTHER ROSBECK DIRECTOR	2 00	X						0	0	0

Part VII

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(18) JUDIT UNGAR RESIGNED DEC 2013 DIRECTOR	2 00	X						0	0	0
(19) FRANK J SASINOWSKI DIRECTOR	2 00	X						0	0	0
(20) WENDY WHITE RESIGNED DEC 2013 DIRECTOR	2 00	X						0	0	0
(21) PETER SALTONSTALL PRESIDENT/CEO	40 00			X				264,154	0	19,720
(22) PAMELA GAVIN COO	40 00				X			196,618	0	19,832
(23) MARK LLOYD CHIEF INFORMATION TECHNOLOGY OFFICER	40 00				X			165,037	0	19,378
(24) RUSSELL TEAGARDEN SVP MEDICAL & SCIENTIFIC AFFAIRS	40 00					X		118,269	0	5,406
(25) MARY COBB VP MEMBERSHIP/STRATEGY	40 00					X		101,081	0	18,292
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)								845,159	0	82,628

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 **5**

		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
CARNEGIE ENDOWMENT FOR INTERNATIONAL PEA 1779 MASSACHUSETTS AVENUE NW WASHINGTON DC 20036	RENT-DC OFFICE	134,088
SANDORMAX 10 WALNUT TREE HILL SANDY HOOK CT 06482	MARKETING/PR/PRINTING	116,169
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 ▶2		

Part VIII

Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns	1a	28,809		
	b	Membership dues	1b	751,040		
	c	Fundraising events	1c	701,000		
	d	Related organizations	1d			
	e	Government grants (contributions)	1e			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	13,679,296		
	g	Noncash contributions included in lines 1a-1f \$				
	h	Total. Add lines 1a-1f		15,160,145		
Program Service Revenue	2a	PATIENT ASSISTANCE AND	Business Code			
			624100	1,418,853	1,418,853	
	b					
	c					
	d					
	e					
	f	All other program service revenue				
	g	Total. Add lines 2a-2f		1,418,853		
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		18,998		18,998
	4	Income from investment of tax-exempt bond proceeds				
	5	Royalties		96,673	96,673	
	6a	Gross rents	(i) Real			
			(ii) Personal			
	b	Less rental expenses				
	c	Rental income or (loss)				
	d	Net rental income or (loss)				
	7a	Gross amount from sales of assets other than inventory	(i) Securities			
			(ii) Other			
			45,594			
	b	Less cost or other basis and sales expenses	28,231			
	c	Gain or (loss)	17,363			
	d	Net gain or (loss)		17,363		17,363
	8a	Gross income from fundraising events (not including \$ 701,000 of contributions reported on line 1c) See Part IV, line 18				
			a	75,744		
	b	Less direct expenses	b	313,035		
	c	Net income or (loss) from fundraising events		-237,291		-237,291
	9a	Gross income from gaming activities See Part IV, line 19				
			a			
	b	Less direct expenses	b			
	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	OTHER EDUCATION SERVIC	541700	49,481	49,481	
	b					
	c					
	d	All other revenue				
	e	Total. Add lines 11a-11d		49,481		
	12	Total revenue. See Instructions		16,524,222	1,565,007	-200,930

Part IX Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States See Part IV, line 21	240,000	240,000		
2	Grants and other assistance to individuals in the United States See Part IV, line 22	11,826,511	11,826,511		
3	Grants and other assistance to governments, organizations, and individuals outside the United States See Part IV, lines 15 and 16	15,000	15,000		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	684,739	317,909	220,812	146,018
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	2,029,406	714,841	1,087,407	227,158
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	81,449	25,442	48,198	7,809
9	Other employee benefits	178,099	58,216	97,816	22,067
10	Payroll taxes	217,613	89,571	93,465	34,577
11	Fees for services (non-employees)				
a	Management				
b	Legal	32,722	21,296	1,731	9,695
c	Accounting	40,000		40,000	
d	Lobbying				
e	Professional fundraising services See Part IV, line 17				
f	Investment management fees				
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	285,883	109,516	51,443	124,924
12	Advertising and promotion	147,287	2,177	362	144,748
13	Office expenses	163,882	56,642	15,248	91,992
14	Information technology	139,464	26,645	75,484	37,335
15	Royalties				
16	Occupancy	414,977	149,943	180,683	84,351
17	Travel	502,125	395,258	87,143	19,724
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	23,713	20,104	1,155	2,454
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization	197,693	88,775	80,188	28,730
23	Insurance	13,733	6,338	5,546	1,849
24	Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24e If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O)				
a	DUES, SUBSCRIPTIONS, AN	24,467	6,907	8,447	9,113
b	EMPLOYEE RELATED COSTS	10,384	1,775	7,175	1,434
c					
d					
e	All other expenses	16,659	470	14,822	1,367
25	Total functional expenses. Add lines 1 through 24e	17,285,806	14,173,336	2,117,125	995,345
26	Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X

Balance Sheet

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

				(A)		(B)
				Beginning of year		End of year
Assets	1	Cash—non-interest-bearing		2,204,442	1	1,532,000
	2	Savings and temporary cash investments		5,288,408	2	5,388,461
	3	Pledges and grants receivable, net			3	
	4	Accounts receivable, net		344,419	4	2,053,809
	5	Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L			5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) 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		54,319	9	104,835
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a2,913,523			
	b	Less accumulated depreciation	10b1,266,225	2,114,138	10c	1,647,298
	11	Investments—publicly traded securities		303,736	11	275,903
	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	752,712
	16	Total assets. Add lines 1 through 15 (must equal line 34)		10,314,641	16	11,755,018
Liabilities	17	Accounts payable and accrued expenses		1,612,194	17	2,170,396
	18	Grants payable		841,947	18	831,378
	19	Deferred revenue		68,333	19	1,774,069
	20	Tax-exempt bond liabilities			20	
	21	Escrow or custodial account liability Complete Part IV of Schedule D			21	
	22	Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L			22	
	23	Secured mortgages and notes payable to unrelated third parties		693,044	23	646,522
	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		3,215,518	26	5,422,365
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here ☒ and complete lines 27 through 29, and lines 33 and 34.					
	27	Unrestricted net assets		4,484,556	27	4,409,025
	28	Temporarily restricted net assets		2,614,567	28	1,923,628
	29	Permanently restricted net assets			29	
	Organizations that do not follow SFAS 117 (ASC 958), 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		7,099,123	33	6,332,653
	34	Total liabilities and net assets/fund balances		10,314,641	34	11,755,018

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	16,524,222
2	Total expenses (must equal Part IX, column (A), line 25)	2	17,285,806
3	Revenue less expenses Subtract line 2 from line 1	3	-761,584
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	7,099,123
5	Net unrealized gains (losses) on investments	5	-4,886
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	6,332,653

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990 ☐ 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? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		No
2b	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	Yes	
2c	If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
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
3b	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.**
▶ **Information about Schedule A (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990*.**

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC	Employer identification number 13-3223946
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Part I

Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is (For lines 1 through 11, check only one box)

1	☐	A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i).
2	☐	A school described in section 170(b)(1)(A)(ii). (Attach Schedule E)
3	☐	A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii).
4	☐	A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state _____
5	☐	An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II)
6	☐	A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v).
7	☒	An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II)
8	☐	A community trust described in section 170(b)(1)(A)(vi) (Complete Part II)
9	☐	An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See section 509(a)(2). (Complete Part III)
10	☐	An organization organized and operated exclusively to test for public safety See section 509(a)(4).
11	☐	An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2) See section 509(a)(3). Check the box that describes the type of supporting organization and complete lines 11e through 11h a ☐ Type I b ☐ Type II c ☐ Type III - Functionally integrated d ☐ Type III - Non-functionally integrated
e	☐	By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2)
f	☐	If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box
g	☐	Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons? (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization? (ii) A family member of a person described in (i) above? (iii) A 35% controlled entity of a person described in (i) or (ii) above?
h	☐	Provide the following information about the supported organization(s)

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

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

Part II

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

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	12,041,663	11,456,178	9,643,015	8,324,575	15,897,806	57,363,237
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	12,041,663	11,456,178	9,643,015	8,324,575	15,897,806	57,363,237
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						57,363,237

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4	12,041,663	11,456,178	9,643,015	8,324,575	15,897,806	57,363,237
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	255,056	138,292	85,651	47,322	115,671	641,992
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income Do not include gain or loss from the sale of capital assets (Explain in Part IV)						
11 Total support (Add lines 7 through 10)						58,005,229
12 Gross receipts from related activities, etc (see instructions)					12	29,673
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 2013 (line 6, column (f) divided by line 11, column (f))	14	98 890 %
15 Public support percentage for 2012 Schedule A, Part II, line 14	15	97 760 %
16a 33 1/3% support test—2013. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	▶	
b 33 1/3% support test—2012. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	▶	
17a 10%-facts-and-circumstances test—2013. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization	▶	
b 10%-facts-and-circumstances test—2012. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization	▶	
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 IIISupport Schedule for Organizations Described in Section 509(a)(2)
(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6.)						

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here ▶						

Section C. Computation of Public Support Percentage		
15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2012 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2013. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
b 33 1/3% support tests—2012. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ▶		

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

Facts And Circumstances Test

Return Reference	Explanation	
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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.** ▶ **Information about Schedule C (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990*.**

OMB No 1545-0047

2013

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, Part V, 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

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

- 1

Provide a description of the organization’s direct and indirect political campaign activities in Part IV
- 2

Political expenditures

▶ \$
- 3

Volunteer hours

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

- 1

Enter the amount of any excise tax incurred by the organization under section 4955

▶ \$
- 2

Enter the amount of any excise tax incurred by organization managers under section 4955

▶ \$
- 3

If the organization incurred a section 4955 tax, did it file Form 4720 for this year?

☐ Yes

☐ No
- 4a

Was a correction made?

☐ Yes

☐ No
- b

If "Yes," describe in Part IV

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

- 1

Enter the amount directly expended by the filing organization for section 527 exempt function activities

▶ \$
- 2

Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities

▶ \$
- 3

Total exempt function expenditures Add lines 1 and 2 Enter here and on Form 1120-POL, line 17b

▶ \$
- 4

Did the filing organization file **Form 1120-POL** for this year?

☐ Yes

☐ No
- 5

Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments For each organization listed, enter the amount paid from the filing organization’s funds Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC) If additional space is needed, provide information in Part IV

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

Part II-A

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

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

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)															
b Total lobbying expenditures to influence a legislative body (direct lobbying)															
c Total lobbying expenditures (add lines 1a and 1b)															
d Other exempt purpose expenditures															
e Total exempt purpose expenditures (add lines 1c and 1d)															
f Lobbying nontaxable amount Enter the amount from the following table in both columns															
<table><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) 2010	(b) 2011	(c) 2012	(d) 2013	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Part II-B

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

For each "Yes" response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.		(a)		(b)
		Yes	No	Amount
1	During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of			
a	Volunteers?		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?	Yes		36,806
j	Total. Add lines 1c through 1i.			36,806
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?			

Part III-A

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

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

Part III-B

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

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

Part IV

Supplemental Information

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

Return Reference	Explanation
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 THE ORGANIZATION'S WEBSITE WHICH WILL, AT TIMES, HAVE PETITIONS FOR INDIVIDUALS TO SIGN ONLINE.

[illegible]

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

▶ **Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b**
▶ **Attach to Form 990.** ▶ **See separate instructions.** ▶ **Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.**

OMB No 1545-0047

2013

Open to Public Inspection

Name of the organization 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 can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☐ Yes ☐ No	

Part II

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

1

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

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

2

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

	Held at the End of the 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, and not on a historic structure listed in the National Register

3

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

4

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

5

Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?

☐ Yes ☐ No

6

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

7

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

8

Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?

☐ Yes ☐ No

9

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

Part III

Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

1a

If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

(ii) Assets included in Form 990, Part X

▶ \$ _____

2

If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

a

Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

b

Assets included in Form 990, Part X

▶ \$ _____

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

Cat No 52283D

Schedule D (Form 990) 2013

Part III

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

- 3

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

a

☐ Public exhibition

b

☐ Scholarly research

c

☐ Preservation for future generations

d

☐ Loan or exchange programs

e

☐ Other
- 4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII
- 5

During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes

☐ No

Part IV

Escrow and Custodial Arrangements. Complete if the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a

Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes

☐ No
- b

If "Yes," explain the arrangement in Part XIII and complete the following table

	Amount
1c	
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 XIII Check here if the explanation has been provided in Part XIII

☐

Part V

Endowment Funds. Complete if the organization answered "Yes" to Form 990, Part IV, line 10.

	(a)Current year	(b)Prior year	b (c)Two years back	(d)Three years back	(e)Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

- 2

Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as

a

Board designated or quasi-endowment

b

Permanent endowment

c

Temporarily restricted endowment

The percentages in lines 2a, 2b, and 2c should equal 100%

3a

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

(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 XIII the intended uses of the organization's endowment funds
- Part VI

Land, Buildings, and Equipment. Complete if the organization answered 'Yes' to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.
- | Description of property | (a) Cost or other basis (investment) | (b)Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|--|--------------------------------------|--------------------------------|------------------------------|----------------|
| 1a Land | | 505,203 | | 505,203 |
| b Buildings | | 767,812 | 197,377 | 570,435 |
| c Leasehold improvements | | 11,910 | 11,116 | 794 |
| d Equipment | | 334,735 | 78,932 | 255,803 |
| e Other | | 1,293,863 | 978,800 | 315,063 |
| Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).) | | | | 1,647,298 |
- Schedule D (Form 990) 2013

Part XI

Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

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

1	Total revenue, gains, and other support per audited financial statements	1	16,832,371
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	-4,886
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	313,035
e	Add lines 2a through 2d	2e	308,149
3	Subtract line 2e from line 1	3	16,524,222
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 12)	5	16,524,222

Part XII

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

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

1	Total expenses and losses per audited financial statements	1	17,598,841
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	313,035
e	Add lines 2a through 2d	2e	313,035
3	Subtract line 2e from line 1	3	17,285,806
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)	5	17,285,806

Part XIII

Supplemental Information

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

Return Reference	Explanation
PART X, LINE 2	NORD ACCOUNTS FOR UNCERTAINTY IN INCOME TAXES IN ACCORDANCE WITH ASC TOPIC INCOME TAXES. THIS STANDARD CLARIFIES THE ACCOUNTING FOR UNCERTAINTY IN TAX POSITIONS AND PRESCRIBES A RECOGNITION THRESHOLD AND MEASUREMENT ATTRIBUTE FOR THE FINANCIAL STATEMENT REGARDING A TAX POSITION TAKEN OR EXPECTED TO BE TAKEN IN A TAX RETURN. NORD HAS DETERMINED THAT THERE ARE NO UNCERTAIN TAX POSITIONS WHICH QUALIFY FOR EITHER RECOGNITION OR DISCLOSURE IN THE FINANCIAL STATEMENTS AT DECEMBER 31, 2013.
PART XI, LINE 2D - OTHER ADJUSTMENTS	FUNDRAISING EXPENSES 313,035
PART XII, LINE 2D - OTHER ADJUSTMENTS	FUNDRAISING EXPENSES 313,035

[illegible]

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.

► Attach to Form 990. ► See separate instructions.

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

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization
NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Employer identification number
13-3223946

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

- 1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ Yes ☐ No
- 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3 Activities per Region (The following Part I, line 3 table can be duplicated if additional space is needed)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
(1) NORTH AMERICA	0	0	GRANT TO RECIPIENT		15,000
(2)					
(3)					
(4)					
(5)					
3a Sub-total	0	0			15,000
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			15,000

Part II

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			NORTH AMERICA	ESTABLISHING A FRAMEWORK TO FACILITATE PHENOTYPIC DELINEATION AND GENE IDENTIFICATION IN DUBOWITZ SYNDROME	15,000	CHECK			BOOK
(2)									
(3)									
(4)									

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

Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 16.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Part IV Foreign Forms

- 1

Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)*

☐

Yes

☒

No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)*

☐

Yes

☒

No
- 3

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

☐

Yes

☒

No
- 4

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

☐

Yes

☒

No
- 5

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

☐

Yes

☒

No
- 6

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

☐

Yes

☒

No

Part V

Supplemental Information

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

990 Schedule F, Supplemental Information

Return Reference	Explanation
PART I, LINE 2	ANY GRANTS GIVEN ARE CLOSELY MONITORED VIA PROGRESS REPORTS COLLECTED ON A MONTHLY BASIS SPENDING COMPARED TO THE GRANT IS REVIEWED AND STAGNANT FUNDS ARE INVESTIGATED

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.

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

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization 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.
Form 990-EZ filers are not required to complete this part.

- 1

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

☐ Mail solicitations
- e

☐ Solicitation of non-government grants
- b

☐ Internet and email solicitations
- f

☐ Solicitation of government grants
- c

☐ Phone solicitations
- g

☐ Special fundraising events
- d

☐ In-person solicitations
- 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.

(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			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
Total ▶						

- 3

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

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		ANNUAL GALA (event type)	DIA CONFERENCE (event type)	(total number)	(add col (a) through col (c))
Revenue	1	Gross receipts	737,900	38,844	776,744
	2	Less Contributions . . .	701,000		701,000
	3	Gross income (line 1 minus line 2)	36,900	38,844	75,744
Direct Expenses	4	Cash prizes			
	5	Noncash prizes . . .			
	6	Rent/facility costs . . .	18,075		18,075
	7	Food and beverages .	78,672	2,460	81,132
	8	Entertainment	57,273	258	57,531
	9	Other direct expenses .	123,623	32,674	156,297
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶			
	11	Net income summary Subtract line 10 from line 3, 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			
	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses . . .			
Direct Expenses	6	Volunteer labor			
	7	Direct expense summary Add lines 2 through 5 in column (d) ▶			
	8	Net gaming income summary Subtract line 7 from line 1, column (d) ▶			

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

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

b If "No," explain _____

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

b If "Yes," explain _____

Does the organization operate gaming activities with nonmembers? ☐ Yes ☐ No

12

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

☐ Yes ☐ No

13

Indicate the percentage of gaming activity operated in

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

14

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

Name 

Address 

15a

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

☐ Yes ☐ No

b

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

c

If "Yes," enter name and address of the third party

Name 

Address 

16

Gaming manager information

Name 

Gaming manager compensation  \$ _____

Description of services provided 

☐ Director/officer

☐ Employee

☐ Independent contractor

17

Mandatory distributions

a

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

☐ Yes ☐ No

b

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

Part IV

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

Return Reference	Explanation
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Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

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

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

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

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization
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. Part II can be duplicated 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) UNIVERSITY OF CALIFORNIA 533 PARNASSUS AVENUE SAN FRANCISCO, CA 94103	94-6036493		30,000		BOOK		ADULT PRIMARY LATERAL SCLEROSIS (PLS)
(2) RUTGERS CANCER INSTITUTE OF NEW JERSEY 195 LITTLE ALBANY STREET NEW BRUNSWICK, NJ 08903	14-6235411		15,000		BOOK		DUBOWITZ SYNDROME
(3) UNIVERSITY OF COLORADO 1250 14TH STREET DENVER, CO 80217	84-6000555		34,000		BOOK		GLYCINE ENCEPHALOPATHY (NONKETOTIC HYPERGLYCINEMIA)
(4) BAYLOR COLLEGE OF MEDICINE ONE BAYLOR PLAZA HOUSTON, TX 77030	74-1613878		30,000		BOOK		GROWTH FAILURE IN CHILDREN WITH CARDIOFACIOCUTANEOUS SYNDROME (CFC)
(5) RUTGERS UNIVERSITY 57 US HIGHWAY 1 NEW BRUNSWICK, NJ 08903	12-2600108		31,000		BOOK		POST-ORGASMIC ILLNESS SYNDROME (POIS)
(6) CREIGHTON UNIVERSITY 2500 CALIFORNIA PLAZA OMAHA, NE 68178	47-0376583		50,000		BOOK		PSEUDOMYXOMA PERITONEI (PMP)
(7) UNIVERSITY OF CALIFORNIA 9500 GILMAN DRIVE LA JOLLA, CA 92093	95-6006144		50,000		BOOK		PSEUDOMYXOMA PERITONEI (PMP)

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.
Part III can be duplicated if additional space is needed.

(a)Type of grant or assistance	(b)Number of recipients	(c)Amount of cash grant	(d)Amount of non-cash assistance	(e)Method of valuation (book, FMV, appraisal, other)	(f)Description of non-cash assistance
(1) PATIENT ASSISTANCE PROGRAMS	2454	11,826,511		BOOK	

Part IV

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

Return Reference	Explanation
SCHEDULE I, PART 1, LINE 2	ANY GRANTS AND SUPPORT GIVEN ARE CLOSELY MONITORED VIA REVIEW OF BACKUP DOCUMENTATION AND PROOF OF EXPENSE

Schedule J
(Form 990)

Department of the Treasury
Internal Revenue Service

Compensation Information

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

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

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

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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 ☐ Travel for companions ☐ Tax idemnification and gross-up payments ☐ Discretionary spending account ☐ Housing allowance or residence for personal use ☐ Payments for business use of personal residence ☐ Health or social club dues or initiation fees ☐ 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 of the expenses described above? If "No," complete Part III to explain	1b	
2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, officers, including the CEO/Executive Director, regarding the items checked in line 1a?	2	
3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director Check all that apply Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III ☐ Compensation committee ☐ Independent compensation consultant ☐ Form 990 of other organizations ☒ Written employment contract ☒ Compensation survey or study ☒ 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? If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III	4c	No
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? If "Yes," to line 5a or 5b, describe in Part III	5b	No
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? If "Yes," to line 6a or 6b, describe in Part III	6b	No
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 Regulations 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	

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

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.

Note. The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation reported as deferred in prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1)PETER SALTONSTALL PRESIDENT/CEO	(i)	264,154	0	0	0	19,720	283,874	0
	(ii)	0	0	0	0	0	0	0
(2)PAMELA GAVIN COO	(i)	196,618	0	0	0	19,832	216,450	0
	(ii)	0	0	0	0	0	0	0
(3)MARK LLOYD CHIEF INFORMATION TECHNOLOGY OFFICER	(i)	165,037	0	0	0	19,378	184,415	0
	(ii)	0	0	0	0	0	0	0

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

Return Reference	Explanation
PART I, LINE 3	THE BOARD OF DIRECTORS REVIEWS EXTERNAL SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS FOR DECISIONS ON THE EXECUTIVE DIRECTOR'S COMPENSATION. THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION.

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.

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

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NATIONAL ORGANIZATION FOR RARE DISORDERS INC

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990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 11	
FORM 990, PART VI, SECTION B, LINE 12C	THE BOARD OF DIRECTORS IS REQUIRED TO COMPLETE AN ANNUAL REVIEW OF THE ORGANIZATION'S CONF LICT OF INTEREST POLICY THE BOARD IS ALSO REQUIRED TO ANNUALLY SIGN OFF AS TO ANY KNOWN C ONFLICTS THAT EXIST
FORM 990, PART VI, SECTION B, LINE 15	THE BOARD OF DIRECTORS REVIEWS EXTERNAL MARKET SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS F OR DECISIONS ON THE EXECUTIVE DIRECTOR COMPENSATION THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION
FORM 990, PART VI, SECTION C, LINE 19	GOVERNING DOCUMENTS ARE MADE AVAILABLE UPON REQUEST
FORM 990, PART XII, LINE 2C	THE BOARD OF DIRECTORS ASSUMES RESPONSIBILITY FOR OVERSIGHT OF THE AUDIT OF IT'S FINANCIAL STATEMENTS AND SLECTION OF AN INDEPENDENT ACCOUNTANT