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DLN: 93493208011551

Return of Organization Exempt From Income Tax

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

OMB No 1545-0047 2010

Open to Public

Department of the Treasury

Form 990

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

Internal Revenue Service Inspection A For the 2010 calendar year, or tax year beginning 01-01-2010 and ending 12-31-2010 D Employer identification number B Check if applicable NATIONAL ORGANIZATION FOR RARE DISORDERS INC 13-3223946 Address change Doing Business As Name change E Telephone number ☐ Initial return Number and street (or P O box if mail is not delivered to street address) Room/suite (203) 744-0100 55 KENOSIA AVENUĖ Terminated **G** Gross receipts \$ 13,420,737 City or town, state or country, and ZIP + 4 DANBURY, CT 068131968 Amended return Application pending Name and address of principal officer **H(a)** Is this a group return for affiliates? Yes No PETER L SALTONSTALL 55 KENOSIA AVENUE ┌ Yes ┌ No **H(b)** Are all affiliates included? DANBURY, CT 068131968 If "No," attach a list (see instructions) H(c) Group exemption number ► Tax-exempt status Website: ► WWW RAREDISEASES ORG K Form of organization
✓ Corporation
☐ Trust
☐ Association
☐ Other ► L Year of formation 1983 M State of legal domicile NY Part I Summary Briefly describe the organization's mission or most significant activities IMPROVE IDENTIFICATION, TREATMENT, AND CURE OF RARE DISEASES THROUGH PROGRAMS OF EDUCATION,

ADVOCACY, RESEARCH AND SERVICE IMPROVE IDENTIFICATION, TREATMENT, AND CURE OF RARE DISEASES

PAGNALII UII CA		THROUGH PROGRAMS OF EDUCATION, ADVOCACY, RESEARCH AND SERVI	CE				
5	2		nore than 25% of its	net as:	sets		
ő.	3	Number of voting members of the governing body (Part VI, line 1a)		3	18		
SAMANA	4	Number of independent voting members of the governing body (Part VI, line 1b)		4	18		
	5	Total number of individuals employed in calendar year 2010 (Part V, line 2a) .		5	53		
ì	6	Total number of volunteers (estimate if necessary)		6	12		
	7a	Total unrelated business revenue from Part VIII, column (C), line 12		7a	C		
	ь	Net unrelated business taxable income from Form 990-T, line 34		7b			
			Prior Year		Current Year		
	8	Contributions and grants (Part VIII, line 1h)	12,041,	663	11,456,179		
<u>∃</u>	9	Program service revenue (Part VIII, line 2g)	2,049	111	1,546,470		
Revenue	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	255	056	149,312		
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)			72,776		
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	14,345	830	13,224,737		
	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	10,531,	850	8,953,825		
	14	Benefits paid to or for members (Part IX, column (A), line 4)			0		
8	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines $5-10$)	2,460	498	2,684,749		
<u>8</u>	16a	Professional fundraising fees (Part IX, column (A), line 11e)			0		
Expenses	ь	Total fundraising expenses (Part IX, column (D), line 25) • 279,168					
	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24f)	1,239	701	1,404,194		
	18	Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	14,232	049	13,042,768		
	19	Revenue less expenses Subtract line 18 from line 12	113	781	181,969		
Rend Balances			Beginning of Curre Year	ent	End of Year		
7	20	Total assets (Part X, line 16)	17,771	948	16,600,875		
\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	21	Total liabilities (Part X, line 26)	3,005	626	1,628,439		
2 2	22	Net assets or fund balances Subtract line 21 from line 20	14,766	322	14,972,436		
Pai	t II	Signature Block					

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

	*****				2011-07-27	
Sign	Signature of officer	Date				
Here	STEPHEN BAJARDI TREASURER					
	Type or print name and title					
	Print/Type preparer's name MICHAEL SOLAKIAN	Preparer's signature	MICHAEL SOLAKIAN	Date 2011-07-27	Check if self- employed •	PTIN
⊃aid ⊃reparer	Firm's name FSOLAKIAN CAIAFA AND COMPA	NY LLC				Firm's EIN
Jse Only	Firm's address 71 HARRISON AVENUE					Phone no 🕨 (203) 483-
,	BRANFORD, CT 064053607					8115
May the IR	S discuss this return with the preparer	shown above? (see	instructions) .			▼ Yes

rm	99	U	(20) 1	U	,
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Page **2**

Par		nt of Program Serv hedule O contains a res				F
1	Briefly describe th	ne organization's missior	1			
	ROVE IDENTIFICA EARCH AND SERVI		ID CURE OF R	ARE DISEASES THRO	OUGH PROGRAMS OF EDUCA	ATION, ADVOCACY,
2	_	on undertake any signific) or 990-EZ?			r which were not listed on	Yes ▼ No
	If "Yes," describe	these new services on S	chedule O			
3	_	on cease conducting, or	_	_		⊤Yes ▼ No
	If "Yes," describe	these changes on Sched	ule O			
4	Section 501(c)(3)		ions and secti	on 4947(a)(1) trusts a	largest program services by eare required to report the amouservice reported	•
4a	(Code) (Expenses \$	9,706,632	ıncludıng grants of \$) (Revenue \$	10,155,179)
	PATIENT SERVICES-P PREMIUMS OR CO-PA		PRESCRIPTION D	RUGS TO UNINSURED AND	NEEDY PATIENTS OR PAYMENT OF T	HEIR HEALTH INSURANCE
4b	(Code) (Expenses \$	1,429,257	ıncludıng grants of \$) (Revenue \$	649,145)
		E UNDERSTANDABLE INFO TO E DATABASE ACCESSIBLE ON T		ES AND THE MEDICAL COM	MUNITY THROUGH PUBLICATIONS, N	EWSLETTERS, BOOKS AND THE
	(Code) (Expenses \$	553,130	ıncludıng grants of \$) (Revenue \$)
	ADVOCACY SERVES A	AS THE LIAISON BETWEEN THE	RARE DISEASE C	OMMUNITY AND THE NATIO	NAL INSTITUTIONS THAT HAVE A DIR	ECT IMPACT ON THEIR HEALTH
4d	Other program se	ervices (Describe in Sch	nedule O)			
	(Expenses \$	479,349 ind	luding grants o	of\$) (Revenue \$)
4e	Total program se	rvice expenses▶\$	12.168.36	58		

Part IV Checklist of Required Schedu	les
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			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 instruction)? 🕏	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		Νο
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		
6	Did the organization maintain any donor advised funds or any similar funds or accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? 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? <i>If "Yes," complete Schedule D, Part II</i>	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		Νο
9	Did the organization report an amount in Part X, line 21, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV	9		No
10	Did the organization, directly or through a related organization, hold assets in term, permanent,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			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line10? 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		No
e	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.	11e		Νo
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		No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI, XII, and XIII	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, XII, and XIII is optional	12b		No
13	Is the organization a school described in section 170(b)(1)(A)(II)? If "Yes," complete Schedule E	13		Νο
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, and program service activities outside the United States? <i>If</i> " <i>Yes,"</i> 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 assistance to any organization or entity located outside the U S? 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 assistance to individuals located outside the U S ? If "Yes," complete Schedule F, Parts III and IV \cdot	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 hospitals? If "Yes," complete Schedule H	20a		Νο
b	If "Yes" to line 20a, did the organization attach its audited financial statement to this return? Note. Some Form 990 filers that operate one or more hospitals must attach audited financial statements (see instructions)	20b		

Par	t IV Checklist of Required Schedules (continued)			
21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21	Yes	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, questions 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J	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? If "Yes," answer lines 24b-24d and complete Schedule K. If "No," go to line 25	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		Νo
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		No
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		Νo
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? If "Yes," complete Schedule L, Part 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? If "Yes," complete Schedule L, Part I	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If "Yes," complete Schedule L, Part II	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III </i>	27		Νo
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)			
а	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part			
	<i>IV</i>	28a		Νo
b	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	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? If "Yes," complete Schedule L, Part IV	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29		Νo
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		Νο
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	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</i> "Yes," complete Schedule R, Part I	33		No
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1	34		No
35	Is any related organization a controlled entity within the meaning of section 512(b)(13)?	35		Νo
а	Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2 $\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ $			
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If</i> "Yes," complete Schedule R, Part V, line 2	36		Νο
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? If "Yes," complete Schedule R, Part VI	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19?	38	Yes	

Part V	Statements Regarding Other IRS Filings and Tax Compliance

	990 (2010)			Page 5
Pa	rt V Statements Regarding Other IRS Filings and Tax Compliance		_	
	Check if Schedule O contains a response to any question in this Part V	•		ı
			Yes	No
1a	Enter the number reported in Box 3 of Form 1096 Enter -0- if not applicable 1a 4			
b	Enter the number of Forms W-2G included in line 1a Enter -0- if not applicable			
	1b 0			
С	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax			
	Statements filed for the calendar year ending with or within the year covered by this			
L	return			
U	If at least one is reported on line 2a, and the organization line an required lederal employment tax returns?	2b	Yes	
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
3a	Did the organization have unrelated business gross income of \$1,000 or more during the			
	year ²	3a		No
	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O	3b		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial			
	account)?	4a		No
b	If "Yes," enter the name of the foreign country ▶			
	See instructions for filing requirements for Form TD F 90-22 1, Report of Foreign Bank and Financial Accounts			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		No
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			No
		5b		110
С	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the	6a		No
	organization solicit any contributions that were not tax deductible?			
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).			
	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and	7a		No.
	services provided to the payor?			
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to	7c		N.o.
d	file Form 8282?	70		No
u	74			
е	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit	l _		l
_	contract?	7e		No
	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		No
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a			
	Form 1098-C?	7h		
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess			
	business holdings at any time during the year?	8		l No
9	Sponsoring organizations maintaining donor advised funds.			11.5
а	Did the organization make any taxable distributions under section 4966?	9a		No
b	Did the organization make a distribution to a donor, donor advisor, or related person?	9b		No
10	Section 501(c)(7) organizations. Enter			
а	Initiation fees and capital contributions included on Part VIII, line 12 10a			
Ь	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club]		
	facilities			
11	Section 501(c)(12) organizations. Enter			
	Gross income from members or shareholders	-		
Ь	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)			
_		1 .		
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
Ь	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.	1		
а	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	13a		
Ь	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	-		
С	Enter the amount of reserves on hand 13c			
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		No

b If "Yes," has it filed a Form 720 to report these payments? *If "No," provide an explanation in Schedule O*...

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.

		n this Part VI					

Se	ction 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			
b	Enter the number of voting members included in line 1a, above, who are independent			
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		Νo
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		Νο
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		Νo
6	Does the organization have members or stockholders?	6	Yes	
7a	Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?	7a	Yes	
b	Are any decisions of the governing body subject to approval by members, stockholders, or other persons?	7b	Yes	
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
а	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
	ection B. Policies (This Section B requests information about policies not required by the Internal			
Re	venue Code.)			
			Yes	No
10a	Does the organization have local chapters, branches, or affiliates?	10a		Νo
	If "Yes," does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?	10b		
11a	Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form?	11a		No
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990			
12a	Does the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes	
ь	Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise			
	to conflicts?	12b	Yes	
С	Does the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this is done	12c	Yes	
13	Does the organization have a written whistleblower policy?	13	Yes	
14	Does 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?			
а	The organization's CEO, Executive Director, or top management official	15a	Yes	
Ь	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," has the organization adopted a written policy or procedure requiring the organization to evaluate its			
	participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?	16b		
Se	ection C. Disclosure			
17	List the States with which a copy of this Form 990 is required to be filed ►WV, WI, WA, VA, UT, TN, SC, RI, P			
	NY NV NM NI NH NC MS MN I	ит мі	= MD	МΔ

- KY, KS, IN, IL, GA, FL, DC, CT, CO, CA, AZ, AL, AK
- 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 make these available. Check all that apply Own website 🔽 Another's website 🔽 Upon request
- Describe in Schedule O whether (and if so, how), the organization makes its governing documents, conflict of interest policy, and financial statements available to the public See Additional Data Table
- State the name, physical address, and telephone number of the person who possesses the books and records of the organization 20 PETER L SALTONSTALL 55 KENOSIA AVENUE DANBURY, CT 06813

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

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

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

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

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

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

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

(A) Name and Title	(B) Average hours	(C) Position (check all that apply)				II	(D) Reportable compensation from the	(E) Reportable compensation from related	(F) Estimated amount of other
	per week (describe hours for related organizations in Schedule O)	Individual trustee or director	Institutional Trustee	organization (W-2/1099-MISC) Highest compensated Officer Officer		organizations (W- 2/1099-	compensation from the organization and related organizations		
(1) PETER SALTONSTALL EXEC DIRECTOR	40 00			х		х	244,823	0	0
(2) FRANK J SASINOWSKI CHAIRMAN	2 00	Х		х			0	0	0
(3) CARLOYN ASBURY VICE CHAIR	2 00	Х		х			0	0	0
(4) JOSEPHINE GRIMA SECRETARY	2 00	Х		х			0	0	0
(5) STEPHEN BAJARDI TREASURER	2 00	х		х			0	0	0
(6) WENDY WHITE DIRECTOR	2 00	х					0	0	0
(7) JAMES BROATCH DIRECTOR	2 00	х					0	0	0
(8) CLAIRE A CENTRELLA DIRECTOR	2 00	Х					0	0	0
(9) BRENDA DUFFY DIRECTOR	2 00	х					0	0	0
(10) NANCY HARRIS DIRECTOR	2 00	х					0	0	0
(11) CHRISTOPHER JENNINGS DIRECTOR	2 00	х					0	0	0
(12) EMIL KAKKIS DIRECTOR	2 00	х					0	0	0
(13) MARYBETH KRUMMENACKER DIRECTOR	2 00	х					0	0	0
(14) DESIREE LYON DIRECTOR	2 00	х					0	0	0
(15) MARY SPRAGUE DIRECTOR	2 00	х					0	0	0
(16) JUDIT UNGAR DIRECTOR	2 00	Х					0	0	0

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

(A) Name and Title		(B) Average hours per	1	(ition that a			11		(D) Reportable compensation from the	(E) Reportable compensation from related		(F) Estima amount o	ated fother
		week (describe hours for related organizations in Schedule O)	Individual trustee or director	Institutional Trustee	Officei	Key employee	Highest compensated employee	Former	organization (W- 2/1099-MISC)	organizations (W- 2/1099- MISC)	s from the		:he on and ed
(17) A	AGNES VARIS CTOR	2 00	x						0		0		0
(18) (DIREC	CHARLENE WALDMAN CTOR	2 00	х						0		0		0
(19) E DIREC	ESTELLE BENSON CTOR	2 00	х						0		0		0
1b	Sub-Total				٠.	<u> </u>		<u> </u>			+		
С	Total from continuation sheets						 -				\top		
d	Total (add lines 1b and 1c) .							 -	244,823				
2	Total number of individuals (inc \$100,000 in reportable comper	-				ted	above) who	received more tha	n			
3	Did the organization list any for on line 1a? <i>If</i> "Yes," complete Sc						mploy •	ee, c	or highest compens	ated employee	3	Yes	No No
4	For any individual listed on line organization and related organization and related organization.										4	Yes	140
5	Did any person listed on line 1a services rendered to the organi									or individual for •	5	1.00	No
Se	ection B. Independent Cor	ntractors											
1	Complete this table for your five \$100,000 of compensation from	e highest compei n the organizatio		ndep	ende	ent o	ontra	ctors	that received mor				
	Na	(A) me and business ad	dress						Desci	(B) ription of services		(C Compen	

2 Total number of independent contractors (including but not limited to those listed above) who received more than

\$100,000 in compensation from the organization 🕨

Daret	90 (2010) /III Statement of Revenue				Pa	age 9
Party	Statement of Revenue			(B) Related or exempt function revenue	(C) Unrelated business revenue	excluded from tax under sections 512, 513, or
Contributions, gifts, grants and other similar amounts	1a Federated campaigns 1a b Membership dues 1b c Fundraising events 1c d Related organizations 1d e Government grants (contributions) 1e f All other contributions, gifts, grants, and similar amounts not included above 2 Q Noncash contributions included in lines 1a-1f \$	51,829 52,589 793,620				514
	h Total. Add lines 1a-1f	ess Code	11,456,179			
Program Service Revenue	INDIGENT CARE DRUG PROGRAMS LITERATURE AND MATERIALS c d e f All other program service revenue g Total. Add lines 2a-2f	900099	1,498,549 47,921 1,546,470	47,921		
	3 Investment income (including dividends, interest and other similar amounts)	-	1,346,470 138,292 72,776			138,29
	(i) Real (ii) Po	ersonal				
-		O ther				
Other Revenue	d Net gain or (loss)		11,020			11,02
	9a Gross income from gaming activities See Part IV, line 19 . a b Less direct expenses					
-	b Less cost of goods sold b c Net income or (loss) from sales of inventory Miscellaneous Revenue Busine t b	ess Code				
	d All other revenue e Total. Add lines 11a-11d 12 Total revenue. See Instructions		13,224,737	1,619,246		149,31

	990 (2010)				Page 10
Par					
	Section $501(c)(3)$ and $501(c)(4)$ organizations mus II other organizations must complete column (A) but are not required to c	•		(D)	
Do no	ot include amounts reported on lines 6b, b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the U.S. See Part IV, line 21	190,000	190,000	general expenses	Скрспэсэ
2	Grants and other assistance to individuals in the U.S. See Part IV, line 22	· · · · · · · · · · · · · · · · · · ·	,		
3	Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16	8,713,825 50,000	8,713,825 50,000		
4	Benefits paid to or for members	0			
5	Compensation of current officers, directors, trustees, and key employees	345,407		345,407	
6	Compensation not included above, to disqualified persons (as defined under section $4958(f)(1)$) and persons described in section $4958(c)(3)(B)$	0			
7	Other salaries and wages	1,842,834	1,648,406		194,428
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)	0			
9	Other employee benefits	322,774	254,317	46,932	21,525
10	Payroll taxes	173,734	134,763	21,361	17,610
а	Fees for services (non-employees) Management	0			·
ь	Legal	49,409	12,236	36,700	473
с	Accounting	12,050	8,047	3,530	473
d	Lobbying	0			
e	Professional fundraising services See Part IV, line 17				
f	Investment management fees	0			
g g	Other	257,320	234,288	23,032	
12	Advertising and promotion	60,884	60,884		
13	Office expenses	145,837	112,059	24,963	8,815
14	Information technology	23,058	22,649	409	0,010
15	Royalties	0			
16	Occupancy	136,338	128,391	6,977	970
17	Travel	108,994	87,483	20,691	820
18	Payments of travel or entertainment expenses for any federal, state, or local public officials	0	07,103	20,031	920
19	Conferences, conventions, and meetings	310,706	310,556		150
20	Interest	45,868	30,723	13,888	1,257
21	Payments to affiliates	0	·		· · · · · · · · · · · · · · · · · · ·
22	Depreciation, depletion, and amortization	83,972	52,863	22,343	8,766
23	Insurance	27,248	21,269	4,876	1,103
24	Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24f If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O)	·			·
а	NEWSLETTER AND DIRECT MAIL EXPENSE	46,656	33,142		13,514
b	REPAIRS AND MAINTENANCE	50,284	34,620	12,184	3,480
С	DUES, SUBSCRIPTIONS AND REGISTRATIONS	35,385	20,508	9,871	5,006
d	d MISCELLANEOUS		7,339	2,068	778
е					
f	All other expenses	0			
25	Total functional expenses. Add lines 1 through 24f	13,042,768	12,168,368	595,232	279,168
26	Joint costs. Check here ► ✓ If following SOP 98-2 (ASC 958-720) Complete this line only if the organization reported in column (B) joint costs from a				· ·
	combined educational campaign and fundraising solicitation	311,852	298,865		12,987

Part X Balance Sheet (A) (B) Beginning of year End of year 250 250 1 15.382.522 2 14.185.928 2 3 3 39,300 4 97,800 4 5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of 5 Schedule L . 6 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) Assets 6 8 8 Prepaid expenses and deferred charges 51,287 87,336 10a Land, buildings, and equipment cost or other basis Complete 2,462,742 10a Part VI of Schedule D 757.147 ь Less accumulated depreciation 10b 1,554,998 **10c** 1,705,595 518,787 738.412 11 11 12 12 Investments—other securities See Part IV, line 11 13 13 Investments—program-related See Part IV, line 11 . . 14 14 5,179 15 5,179 15 16 17,771,948 16 16,600,875 **Total assets.** Add lines 1 through 15 (must equal line 34) . . . 60,247 17 121,839 17 Accounts payable and accrued expenses . 18 517,108 18 518,491 211.370 19 1.613.150 19 20 20 Liabilities 21 21 Escrow or custodial account liability $Complete\ Part\ IV\ of\ Schedule\ D$. . 22 Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified 22 815.121 23 23 776.739 Secured mortgages and notes payable to unrelated third parties . . 24 24 Unsecured notes and loans payable to unrelated third parties 25 25 Other liabilities Complete Part X of Schedule D 26 3.005.626 26 1,628,439 Total liabilities. Add lines 17 through 25 Organizations that follow SFAS 117, check here ▶ 🔽 and complete lines 27 Balances through 29, and lines 33 and 34. 27 Unrestricted net assets 6,238,552 27 6.074.123 Temporarily restricted net assets 8,527,770 8,898,313 28 28 Fund 29 29 Permanently restricted net assets Organizations that do not follow SFAS 117, check here ▶ □ and complete lines 30 through 34. 5 30 30 Capital stock or trust principal, or current funds Assets 31 Paid-in or capital surplus, or land, building or equipment fund 31 32 32 Retained earnings, endowment, accumulated income, or other funds ¥ 14,766,322 33 14,972,436 33 Total net assets or fund balances 34 Total liabilities and net assets/fund balances 17.771.948 16,600,875

Pa	Check if Schedule O contains a response to any question in this Part XI						
1	Total revenue (must equal Part VIII, column (A), line 12)	1		13.3	224,73		
2	Total expenses (must equal Part IX, column (A), line 25)	2					
3	Revenue less expenses Subtract line 2 from line 1	3	, ,		181,969		
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	14,766,32				
5	Other changes in net assets or fund balances (explain in Schedule O)	5			24,14		
6	Net assets or fund balances at end of year Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))						
Pai	rt XII Financial Statements and Reporting						
	Check if Schedule O contains a response to any question in this Part XII			୮	•		
				Yes	No		
1	Accounting method used to prepare the Form 990 Cash Accrual Other						
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		2a		No		
Ь	Were the organization's financial statements audited by an independent accountant?		2b	Yes			
c	If "Yes," to 2a or 2b, does the organization have a committee that assumes responsibility for oversight of 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 i	n					
	Schedule O		2c	Yes			
d	If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were in a separate basis, consolidated basis, or both	ssued					
	▼ Separate basis						
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in th Single Audit Act and OMB Circular A-133?	е	3a		No		
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the raudit or audits, explain why in Schedule O and describe any steps taken to undergo such audits	equired	3b				

Employer identification number

OMB No 1545-0047

OMB No 1545-004

2010

Open to Public Inspection

SCHEDULE A

(Form 990 or 990EZ)

Department of the Treasury

Internal Revenue Service

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

Public Charity Status and Public Support

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

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC

IVALIC	JIVAL OF	13-3223946							
Pa	rt I	Reason for Public Charity Status (All organizations must complete this part.) See instru	ctions						
		ization is not a private foundation because it is (For lines 1 through 11, check only one box)	00000						
1	Γ	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 hospital's name, city, and state)(iii). Ente	r the					
5	Γ	An organization operated for the benefit of a college or university owned or operated by a governmental unsection 170(b)(1)(A)(iv). (Complete Part II)	ıt describe	d in					
6	Γ	A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v).							
7	Γ	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	Г	_							
9	<u> </u>	An organization that normally receives (1) more than 331/3% 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 th	an 331/3%	of					
		its support from gross investment income and unrelated business taxable income (less section 511 tax) i	rom busine	esses					
		acquired by the organization after June 30, 1975 See section 509(a)(2). (Complete Part III)							
10	\sqcap	An organization organized and operated exclusively to test for public safety Seesection 509(a)(4).							
11	Γ	An organization organized and operated exclusively for the benefit of, to perform the functions of, or to car one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2) See see 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		a)(3).	Check				
e	Γ	By checking this box, I certify that the organization is not controlled directly or indirectly by one or more other than foundation managers and other than one or more publicly supported organizations described in 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 sucheck this box	ipporting o	rganız	ation,				
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)		Yes	No				
		and (III) below, the governing body of the the supported organization?	11g(i)						
		(ii) a family member of a person described in (i) above?	11g(ii)						
_		(iii) a 35% controlled entity of a person described in (i) or (ii) above?	11g(iii)						
h		Provide the following information about the supported organization(s)							

(i) Name of supported organization	(ii) EIN		(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 US?		(vii) A mount of 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.)

	ection A. Public Support	organización i	ano to quamy t	macr the tests	noted below, pre	sase complete	rare III.		
		T		1					
Cale	endar year (or fiscal year beginning in)	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total		
1	Gifts, grants, contributions, and								
	membership fees received (Do not								
	ınclude any "unusual								
	grants ")								
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								
5	The portion of total contributions by								
	each person (other than a								
	governmental unit or publicly								
	supported organization) included on								
	line 1 that exceeds 2% of the								
	amount shown on line 11, column								
	(f)			+					
6	Public Support. Subtract line 5 from line 4						0		
S	ection B. Total Support	_1	.1	<u> </u>			<u> </u>		
	endar year (or fiscal year beginning	() 2006	(1) 2007	() 2000	(1) 2000	() 2010	/6> T		
	ın) >	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total		
7	A mounts from line 4								
8	Gross income from interest,								
0	dividends, payments received on								
	securities loans, rents, royalties								
	and income from similar								
	sources								
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)								
12	Gross receipts from related activities	es, etc (See inst	ructions)			12			
13	First Five Years If the Form 990 is f	for the organization	nn's first second	third fourth or i	fifth tay vear as a	501(c)(3) organ	ızatıon		
	check this box and stop here	or the organization	on a mat, second	, tillia, loaitii, or i	intilitax year as a	501 (c)(5) 01gan	▶ □		
							- 1		
S	ection C. Computation of Pub	lic Support P	ercentage						
14	Public Support Percentage for 2010) (line 6 column (f) dıvıded by lıne	11 column (f))		14	0 %		
15	Public Support Percentage for 2009	Schedule A, Par	rt II, line 14			15			
16a	33 1/3% support test-2010. If the	organization did	not check the bo	x on line 13, and	line 14 is 33 1/3%	or more, check	this box		
	and stop here. The organization qua				,	,	▶ □		
b	33 1/3% support test-2009. If the	•			5a, and line 15 is 3	3 3 1/3% or more	, check this		
	box and stop here. The organization	_			,		´ ▶ ┌		
17a	10%-facts-and-circumstances test-				ne 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				,		▶ □		
Ь	10%-facts-and-circumstances test-	–2009. If the ora:	anization did not	check a box on li	ne 13, 16a, 16b. d	r 17a and line	•		
_	15 is 10% or more, and if the organ								
	Explain in Part IV how the organizat			•		-	у		
	supported organization				_	,	▶ □		
18	Private Foundation If the organizati	on did not check	a box on line 13	, 16a, 16b, 17a o	r 17b, check this	box and see	•		
	instructions		=-,	, -,	,		▶ □		

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

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Se	ction A. Public	c Support						
Cale	ndar year (or fisc		(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
1	Gifts, grants, cor membership fees not include any " grants")	ntributions, and received (Do	11,653,938	11,438,927	10,475,348	12,041,663	11,456,178	57,066,05
2	Gross receipts fr merchandise solo performed, or fac in any activity th the organization' purpose	d or services ilities furnished at is related to s tax-exempt	2,672,826	2,272,759	1,873,704	2,049,111	1,619,245	10,487,64
3	Gross receipts fr are not an unrela business under s							
4	Tax revenues lev organization's be paid to or expend behalf	nefit and either ded on its						
5	The value of serv furnished by a go to the organization charge	vernmental unit on without						
6 7a	Total. Add lines: A mounts include and 3 received fr	d on lines 1, 2,	14,326,764	13,711,686	12,349,052	14,090,774	13,075,423	67,553,69
	persons A mounts include 3 received from o disqualified perso the greater of \$5 the amount on lir	d on lines 2 and other than ons that exceed ,000 or 1% of ne 13 for the year						
8 8	Add lines 7a and Public Support (S from line 6)							67,553,69
Se	ction B. Total	Support						
Cale	•	fiscal year	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) 2010	(f) Total
9	beginning A mounts from lir		14,326,764	13,711,686	12,349,052	14,090,774	13,075,423	67,553,69
10a	Gross income fro		, ,	, ,	, ,	, ,	, ,	
	dividends, paymon securities loa royalties and inc similar sources	ents received ns, rents, ome from	453,004	617,658	524,158	255,056	138,292	1,988,16
b	Unrelated busine income (less sec taxes) from businecquired after Ju	tion 511 nesses						
c	Add lines 10a ar		453,004	617,658	524,158	255,056	138,292	1,988,16
11	Net income from business activiti in line 10b, whet business is regu	es not included her or not the						
12	Other income D gain or loss from capital assets (E IV)	the sale of						
13	Total support (A 11 and 12)		14,779,768	14,329,344	12,873,210	14,345,830	13,213,715	69,541,86
14	First Five Years I check this box ar	f the Form 990 is f nd stop here	or the organization	on's first, second,	thırd, fourth, or f	ifth tax year as a	section501(c)(3)) organization, ►
Se		utation of Pub						
15	Public Support P	ercentage for 2010	(line 8 column (f	divided by line	13 column (f))		15	97 140 %
16	Public support pe	rcentage from 200	9 Schedule A, Pa	art III, line 15			16	97 100 %
Se	ction D. Comp	utation of Inve	estment Inco	me Percenta	1e			
Se		outation of Invented for 2				(f))	17	2 860 %
	Investment incor		2010 (line 10c co	lumn (f) dıvıded b	y line 13 column	(f))	17	2 860 %

19a 33 1/3% support tests—2010. If the organization did not check the box on line 14, and line 15 is more than 33 1/3% and line 17 is no more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported

organization

33 1/3% support tests—2009. 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 **Private Foundation** If the organization did not check a box on line 14, 19a or 19b, check this box and see instructions

Schedule A (Fo	orm 990 or 990-EZ) 2010	Pag
Part IV	Supplemental Information. Supplemental Information. Complete this required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. additional information. (See instructions).	•

Facts And	Circumstances	Test

Schedule A (Form 990 or 990-EZ) 2010

DLN: 93493208011551

SCHEDULE C (Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527 ► Complete if the organization is described below.

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

OMB No 1545-0047

Inspection

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

- 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 ganization answered "Yes," to Form 990, Part IV, Line 5 (Proxy Tax) or Form 990-F7, Part V, line 35a (Proxy Tax) then

● Se	ction 501(c)(4), (5), or (6) organi	zations Complete Part III		· · · · · · · · · · · · · · · · · · ·						
	me of the organization FIONAL ORGANIZATION FOR RARE DISO	RDERS INC		Employer ide	ntıfıcatıon number					
				13-3223946						
Par	t I-A Complete if the or	ganization is exempt und	er section 501(c) or is a section 52	7 organization.					
1	Provide a description of the or	ganızatıon's dırect and ındırect po	olitical campaign act	tivities in Part IV						
2	Political expenditures			▶	\$					
3	V olunteer hours									
Par	t I-B Complete if the or	ganization is exempt und	er section 501(c)(3).						
1		e tax incurred by the organization	_		\$					
2	Enter the amount of any excise	e tax incurred by organization ma	nagers under sectio	n 4955 ►	\$					
3	If the organization incurred a s	ection 4955 tax, did it file Form	4720 for this year?		☐ Yes ☐ No					
4a	Was a correction made?				┌ Yes					
b	If "Yes," describe in Part IV									
Par	t I-C Complete if the or	ganization is exempt und	er section 501(c) except section 50	1(c)(3).					
1	Enter the amount directly expe	ended by the filing organization fo	r section 527 exem	pt function activities 🕨	\$					
2	Enter the amount of the filing of exempt funtion activities	organization's funds contributed to	o other organization	s for section 527 ▶	\$					
3	Total exempt function expendi	tures Add lines 1 and 2 Enter he	ere and on Form 112	20-POL, line 17b ►	\$					
4	Did the filing organization file I	Form 1120-POL for this year?			⊤ Yes					
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) A mount paid from filing organization's funds If none, enter -0-	(e) A mount of political contributions received and promptly and directly delivered to a separate political organization If none, enter -0-					

Sc	hedule C (Form 990 or 990-EZ) 2010						Page 2
P	art II-A Complete if the organization under section 501(h)).	is ex	cempt under	section 501(c)(3) and fi	led Form 5768	
A B	Check If the filing organization belongs to a Check If the filing organization checked bo			" provisions apply	/		
	Limits on Lobbying E (The term "expenditures" means a)		(a) Filing Organization's Totals	(b) Affiliated Group Totals
<u>1</u> a	Total lobbying expenditures to influence public o	pinion	(grass roots lob	oyıng)			
b	Total lobbying expenditures to influence a legisl	atıve b	ody (direct lobby	ıng)			
c	Total lobbying expenditures (add lines 1a and 1	b)					
d	Other exempt purpose expenditures						
е	Total exempt purpose expenditures (add lines 1	c and :	Ld)				
f	Lobbying nontaxable amount Enter the amount columns						
	If the amount on line 1e, column (a) or (b) is:	The	lobbying nontaxa	ble amount is:			
	Not over \$500,000	20%	of the amount on lin	e 1e			
	Over \$500,000 but not over \$1,000,000	\$100	,000 plus 15% of the	excess over \$500,00	0		
	Over \$1,000,000 but not over \$1,500,000	\$175	,000 plus 10% of the	excess over \$1,000,0	000		
	Over \$1,500,000 but not over \$17,000,000	\$225	,000 plus 5% of the	excess over \$1,500,00	00		
	Over \$17,000,000	\$1,00	00,000				
	Grassroots nontaxable amount (enter 25% of lir	ne 1 f)					
_	Subtract line 1g from line 1a If zero or less, ent	-					
i	Subtract line 1f from line 1c If zero or less, ente	er - 0 -					
j	If there is an amount other than zero on either li section 4911 tax for this year?	ne 1h d	or line 11, did the	organization file F	orm 4720 rep	orting	┌ Yes ┌ No
	4-Year Av (Some organizations that made a columns below. See t	secti	on 501(h) ele		havè to co		ne five
	Lobbying Exp	endit	ures During 4	l-Year Averag	jing Period		
	Calendar year (or fiscal year						

	Lobbying Expenditures During 4-Year Averaging Period										
	Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) Total					
2a	Lobbying non-taxable amount										
b	Lobbying ceiling amount (150% of line 2a, column(e))										
С	Total lobbying expenditures										
d	Grassroots non-taxable amount										
e	Grassroots ceiling amount (150% of line 2d, column (e))										
f	Grassroots lobbying expenditures										

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

	(election under section 501(h)).	1:	a)		(b)	
		Yes	No	,	Mour	nt
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					
а	V olunteers?	Yes]		
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	Yes				
c	Media advertisements?		Νo			
d	Mailings to members, legislators, or the public?	Yes				824
е	Publications, or published or broadcast statements?	Yes				772
f	Grants to other organizations for lobbying purposes?		Νo			
g	Direct contact with legislators, their staffs, government officials, or a legislative body?	Yes				2,614
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?	Yes				
i	Other activities? If "Yes," describe in Part IV		Νo			
j	Total lines 1c through 1i					4,210
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		Νo			
Ь	If "Yes," enter the amount of any tax incurred under section 4912			1		
С	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?		I			
Pai	t III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(6).	501(c)(5),	or se	ectio	n
			_		Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?		L	1		
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?			2		
3	Did the organization agree to carryover lobbying and political expenditures from the prior year?			3		
	t III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(6) if BOTH Part III-A, lines 1 and 2 are answered "No" OR if Part I answered "Yes".	II-A,			ectio	n
1	Dues, assessments and similar amounts from members	1				
2	Section 162(e) non-deductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).					
a b	Current year Carryover from last year	2a 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				
	art IV Supplemental Information	1 -				

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

Ident if ier Return Reference Explanation efile GRAPHIC print - DO NOT PROCESS

As Filed Data

DLN: 93493208011551

OMB No 1545-0047

Open to Public

SCHEDULE D (Form 990)

Department of the Treasury

Supplemental Financial Statements

► Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11, or 12. ► Attach to Form 990. ► See separate instructions.

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC

Internal Revenue Service Inspection **Employer identification number** 13-3223946 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 Total number at end of year Aggregate contributions to (during year) 3 Aggregate grants from (during year) Aggregate value at end of year Did the organization inform all donors and donor advisors in writing that the assets held in donor advised ┌ No funds are the organization's property, subject to the organization's exclusive legal control? Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit Part II Conservation Easements. Complete if the organization answered "Yes" to Form 990, Part IV, line 7. Purpose(s) of conservation easements held by the organization (check all that apply) Preservation of land for public use (e.g., recreation or pleasure) Preservation of an historically importantly land area Protection of natural habitat Preservation of a certified historic structure Preservation of open space Complete lines 2a-2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year Held at the End of the Year Total number of conservation easements 2a Total acreage restricted by conservation easements 2b Number of conservation easements on a certified historic structure included in (a) 2c Number of conservation easements included in (c) acquired after 8/17/06 2d

3	Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during
	the taxable year 🗠
4	Number of states where property subject to conservation easement is located 🛌
5	Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?
6	Staff and volunteer hours devoted to monitoring, inspecting and enforcing conservation easements during the year 🛌
7	A mount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶ \$
8	Does each conservation easement reported on line 2(d) above satisfy the requirements of section $170(h)(4)(B)(I)$ and $170(h)(4)(B)(II)$?
9	In Part XIV, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements

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

- If the organization elected, as permitted under SFAS 116, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items
- If the organization elected, as permitted under SFAS 116, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items
 - (i) Revenues included in Form 990, Part VIII, line 1

(ii) Assets included in Form 990, Part X

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

Revenues included in Form 990, Part VIII, line 1

Assets included in Form 990, Part X

For Privacy Act and Paperwork Reduction Act Notice, see the Intructions for Form 990 Cat No 52283D

Schedule D (Form 990) 2010

Paru	Organizations Maintaining Co	llections of Art	t, His	stori	<u>cal Tr</u>	<u>easu</u>	res, or Ot	<u>her</u>	Similar	Asse	ts (co	ontinued)
3	Using the organization's accession and othe items (check all that apply)	r records, check an	ny of th	ne foll	owing t	hat ar	e a sıgnıfıcan	ıt us	e of its coll	ectior	l	
а	Public exhibition		d	Γ	Loan o	rexcl	hange progra	ms				
b	Scholarly research		e	Γ	Other							
c	Preservation for future generations											
4	Provide a description of the organization's co	ollections and expla	ain hov	w the	y furthe	r the o	organization's	exe	empt purpos	se in		
5	During the year, did the organization solicit of assets to be sold to raise funds rather than t			,					lar	Г	Yes	∏ No
Par	Part IV, line 9, or reported an an						n answered	"Ye	es" to Forn	n 990	,	
1a	Is the organization an agent, trustee, custod included on Form 990, Part X?	ıan or other ınterm	ediary	for c	ontribut	tions o	or other asse	ts n	ot	Γ	Yes	┌ No
b	If "Yes," explain the arrangement in Part XIV	/ and complete the	follow	ving t	able					A mou	nt	
c	Beginning balance						1	.c				
d	Additions during the year							.d				
e	Distributions during the year						<u> </u>	e .				
f	Ending balance							f				
2a	Did the organization include an amount on Fo	orm 990 Part V Jur	na 212	,			ــــ	.			Yes	✓ No
			ie Zīr							'	165)* NO
	If "Yes," explain the arrangement in Part XIV t V Endowment Funds. Complete i		n and	wor	ad "Voc	:" to I	Form 990 [Dart	· TV line 1	<u></u>		
ГС	Endowment I dids. Complete	(a)Current Year)Prior `					hree Years Ba		Four Y	ears Back
1a	Beginning of year balance											
b	Contributions											
с	Investment earnings or losses											
d	Grants or scholarships											
e	Other expenditures for facilities and programs											
f	Administrative expenses											
g	End of year balance											
2	Provide the estimated percentage of the yea	r end balance held	as									
а	Board designated or quasi-endowment											
ь	Permanent endowment											
с	Term endowment ▶											
3a	Are there endowment funds not in the posses	ssion of the organiz	ation	thata	are held	and a	dministered :	for t	he			
	organization by	_							_		Yes	No
	(i) unrelated organizations							•	_	3a(i)		
_	(ii) related organizations								🖺	Ba(ii)		<u> </u>
	If "Yes" to 3a(II), are the related organizatio	•						•		3b		
4	Describe in Part XIV the intended uses of the tVI Investments—Land, Buildings)() D:	art V lina 1	^				
Pai	t VI Investments—Land, Buildings	s, and Equipme	:111. 5				·			T		
	Description of investment				Cost or ((b)Cost or oth basis (other)		(c) Accumula depreciatio		(d) Bo	ok value
1a l	and		•				505,2	203				505,203
b i	Buildings		•				761,5	97	13	8,290		623,307
	_easehold improvements						11,9	10		3,970		7,940
c l												
	Equipment		•				1,184,0	32	61	1,887		569,145
d i	Equipment	<u> </u>	•						61	1,887		569,145

Investments—Other Securities. See	roi ili 990, Pait X, ilile 12		
(a) Description of security or category	(b)Book value	(c) Method of valuation	
(including name of security)	(2)2001111111	Cost or end-of-year market v	alue
(1)Financial derivatives			
(2)Closely-held equity interests			
Other			
O ther			
Total. (Column (b) should equal Form 990, Part X, col (B) line 12)			
		12	
Part VIII Investments—Program Related. See	: гогиг ээо, rait x, ime . T		
(a) Description of investment type	(b) Book value	(c) Method of valuation	ماليم
		Cost or end-of-year market v	aiue
Total. (Column (b) should equal Form 990, Part X, col (B) line 13)			
Part IX Other Assets. See Form 990, Part X, In	e 15.		
(a) Descrip	tion	(b) Book v	alue
Total. (Column (b) should equal Form 990, Part X, col.(B) line 1	5.)		
Part X Other Liabilities. See Form 990, Part X	, line 25.		
Part X Other Liabilities. See Form 990, Part X	, line 25.		
Part X Other Liabilities. See Form 990, Part X 1 (a) Description of Liability	, line 25.		
Part X Other Liabilities. See Form 990, Part X 1 (a) Description of Liability	, line 25.		
Part X Other Liabilities. See Form 990, Part X 1 (a) Description of Liability	, line 25.		
Part X Other Liabilities. See Form 990, Part X 1 (a) Description of Liability	, line 25.		
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Part X Other Liabilities. See Form 990, Part X 1 (a) Description of Liability	, line 25.		
Part X Other Liabilities. See Form 990, Part X 1 (a) Description of Liability Federal Income Taxes	, line 25.		
Part X Other Liabilities. See Form 990, Part X (a) Description of Liability	, line 25.		

Par	Reconciliation of Change in Net Assets from Form 990 to Financial Statemen	nts	
1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	13,224,737
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	13,042,768
3	Excess or (deficit) for the year Subtract line 2 from line 1	3	181,969
4	Net unrealized gains (losses) on investments	4	
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV)	8	
9	Total adjustments (net) Add lines 4 - 8	9	
10	Excess or (deficit) for the year per financial statements. Combine lines 3 and 9	10	181,969
	XII Reconciliation of Revenue per Audited Financial Statements With Revenue p		<u> </u>
1	Total revenue, gains, and other support per audited financial statements	1	13,519,097
2	A mounts included on line 1 but not on Form 990, Part VIII, line 12		
а	Net unrealized gains on investments		
b	Donated services and use of facilities 2b 270,215		
c	Recoveries of prior year grants		
d	Other (Describe in Part XIV)		
e	Add lines 2a through 2d	2e	294,360
3	Subtract line 2e from line 1	3	13,224,737
4	A mounts included on Form 990, Part VIII, line 12, but not on line 1		
а	Investment expenses not included on Form 990, Part VIII, line 7b . 4a		
b	Other (Describe in Part XIV) 4b		
c	Add lines 4a and 4b	4c	
5	Total Revenue Add lines 3 and 4c. (This should equal Form 990, Part I, line 12)	5	13,224,737
	Reconciliation of Expenses per Audited Financial Statements With Expenses	per	
1	Total expenses and losses per audited financial statements	1	13,312,983
2	A mounts included on line 1 but not on Form 990, Part IX, line 25		
а	Donated services and use of facilities		
b	Prior year adjustments		
	Other losses		
С			
c d	Other (Describe in Part XIV) 2d		
	Other (Describe in Part XIV)	2e	270,215
d	Other (Describe in Part XIV)	2e 3	
d e	Other (Describe in Part XIV)	-	
d e 3	Other (Describe in Part XIV)	-	
d e 3 4	Other (Describe in Part XIV)	3	
d e 3 4 a	Other (Describe in Part XIV)	-	270,215 13,042,768 13,042,768

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

Identifier Return Reference Explanation

efile GRAPHIC print - DO NOT PROCESS

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OMB No 1545-0047

Open to Public **Inspection**

SCHEDULE F (Form 990)

Department of the Treasury

to Part I

c Totals (add lines 3a and 3b)

Internal Revenue Service

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

▶ Attach to Form 990. ▶ See separate instructions.

Statement of Activities Outside the United States

Name of the organization

Employer identification number

AT	IONAL ORGANIZATION FOR RA	ARE DISORDE	RS INC			
		2130 ((5)			13-32239	946
Pa	rt I General Informatio "Yes" to Form 990, Pa			he United States. C	omplete if the org	janization answered
1	For grantmakers. Does the assistance, the grantees' eligible the grants or assistance?	organization r gibility for the	maıntaın record grants or assı	stance, and the select	ion criteria used to	award
2	For grant makers. Describe in Pa United States	art V the organi	zatıon's procedu	res for monitoring the us	e of grant funds outs	ıde the
3	Activites per Region (Use Part	V ıf addıtıonal s	pace is needed)		
	(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region or independent contractors	region (by type) (e g ,	(e) If activity listed in (d program service, desc specific type of service(s) in region	ribe expenditures for region/investments
	Europe			GRANTS TO RECIPIENTS	RESEARCH GRANT	50,000
	Sub-total Total from continuation sheets					50,000
-		1	1	•	i	

50,000

(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) A mount of cash grant	(f) Manner of cash disbursement	(g) A mount of of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		Europe	MEDICAL RESEARCH	50,000	СНЕСК		N/A	FMV
_								
			sted above that are i ee or counsel has pro					1

Part III	Grants and Ot	her Assistance to	Individuals	Outside the Unit	ed States. Complete i	f the organization a	nswered "Yes" to Form !	990, Part IV, line 16.
	Use Part V if add	ditional space is ne	eded.		·			

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) A mount of cash grant	(e) Manner of cash disbursement	(f) A mount of non-cash	(g) Description of non-cash	(h) Method of valuation
					assistance	assistance	(book, FMV, appraisal, other)
			<u> </u>			1	
			<u>. </u>		!		
			<u>. </u>				
			<u> </u>		!		
			<u> </u>		!		
			<u> </u>		!		
			<u> </u>		!		
			1		!		
			1		,		

Part IV Foreign Forms

1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 926 (see instructions for Form 926)	Γ	Yes	₹	Νo
2	Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to file Form 3520 and/or Form 3520-A. (see instructions for Forms 3520 and 3520-A)	Γ	Yes	~	Νo
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)	Г	Yes	굣	Νo
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621, Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see instructions for Form 8621)	Г	Yes	্	Νo
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)	Г	Yes	্	Νo
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).	Г	Yes	⊽	Νo

Schedule F (Form 990) 2010

information. Identifier	ReturnReference	Explanation
14011111101	T. G.	Explanation

DLN: 93493208011551

OMB No 1545-0047

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.

Inspection

Name of the organization **Employer identification number** NATIONAL ORGANIZATION FOR RARE DISORDERS INC 13-3223946 Part I Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17. Indicate whether the organization raised funds through any of the following activities. Check all that apply Mail solicitations e Solicitation of non-government grants Solicitation of government grants Internet and e-mail solicitations Special fundraising events Phone solicitations In-person solicitations 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? If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization Form 990-EZ filers are not required to complete this table (i) Name and address of (ii) Activity (iii) Did (iv) Gross receipts (v) A mount paid to (vi) A mount paid to ındıvıdual fundraiser have from activity (or retained by) (or retained by) or entity (fundraiser) custody or fundraiser listed in organization col (i) control of contributions? Yes

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

Pai	rt II	Fundraising Events. Com more than \$15,000 on Form				
			(a) Event #1 BANQUET (event type)	(b) Event #2 (event type)	(c) O ther Events (total number)	(d) Total Events (Add col (a) through col (c))
₽	1	Gross receipts	793,620			793,620
Revenue	2	Less Charitable contributions	793,620			793,620
<u>~</u>	3	Gross income (line 1 minus line 2)				
	4	Cash prizes				
မာ	5	Non-cash prizes				
Expenses	6	Rent/facility costs				
ă	7	Food and beverages				
Direct	8	Entertainment				
莅	9	Other direct expenses .				
	10	Direct expense summary Add line	es 4 through 9 ın column	(d)	🛌	
	11	Net income summary Combine li	nes 3 and 10 ın column (d)		
Par	t II	Gaming. Complete if the or \$15,000 on Form 990-EZ, lir		"Yes" to Form 990, Pa	rt IV, line 19, or repo	orted more than
Revenue			(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) O ther gaming	(d) Total gaming (Add col (a) through col (c))
	1	Gross revenue				
နွ	2	Cash prizes				
xpenses	3	Non-cash prizes				
ш	4	Rent/facility costs				
Direct	5	Other direct expenses				
	6	Volunteer labor	Γ Yes % Γ No	☐ Yes % ☐ No	┌ Yes % ┌ No	
		Direct expense summary Add lines				
	8	Net gaming income summary Com	bine lines 1 and 7 in colu	ımn (d)	<u> </u>	
9		er the state(s) in which the organiza the organization licensed to operate				
a b		tne organization licensed to operate No," Explain		n orthese states?		· I Yes I No
10a b		re any of the organization's gaming l Yes," Explain			the tax year?	· · Fyes Fno

11	Does the organization operate ga	aming activities with nonmembers?		Г үе	s Γ_{No}
12	Is the organization a grantor, be	neficiary or trustee of a trust or a mer	nber of a partnership or other entity		
	formed to administer charitable (jaming?		Г _{Yе}	s Γ_{No}
13	Indicate the percentage of gamin	ng activity operated in			
а	The organization's facility			1	
b	An outside facility			,	
14	Provide the name and address or records	f the person who prepares the organız	ation's gaming/special events books and	d	
	Name 🟲				
	Address 🟲				
15a		ntract with a third party from whom th		_	_
					s No
ь		ning revenue received by the organizated by the third party 🟲 \$	ation > \$ and the		
c	If "Yes," enter name and address	5			
	Name 🟲				
	Address 🟲				
16	Gaming manager information				
	Name 🟲				
	Gaming manager compensation l	* \$			
	Description of services provided	>			
	Director/officer	Employee	Independent contractor		
17	Mandatory distributions				
а		er state law to make charitable distrib		_	_
p.				· Ye	s No
D		required under state law distributed activities during the tax year - \$	to other exempt organizations or spent		
Par			r responses to question on Schedul	e G (see	
	Identifier	ReturnReference	Explanation		

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Schedule I (Form 990)

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

OMB No 1545-0047

DLN: 93493208011551

Department of the Treasury Internal Revenue Service

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

Inspection

Employer identification number Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC 13-3223946 Part I General Information on Grants and Assistance Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and √ Yes Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States Part II Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Part II can be duplicated if additional space is needed. (c) IRC Code section 1 (a) Name and address of **(b)** EIN (d) A mount of cash (e) A mount of non-(f) Method of (g) Description of (h) Purpose of grant organization ıf applıcable cash valuation non-cash assistance or assistance grant or government assistance (book, FMV, appraisal, other) (1) UNIV OF PITTSBURGH 25-0965591 50,000 FMV N/A MEDICAL RESEARCH UPCI PAVILLION PITTSBURGH, PA 15213 (2) UC-SAN FRANCISCO 94-6036493 50,000 FΜV N/A MEDICAL 513 PARNASSUS AVE RESEARCH SAN FRANCISCO, CA 94143 (3) UNIV OF 30.000 N/A MEDICAL 23-1352685 FMV PENNSYLVANIA3400 RESEARCH SPRUCE ST PHILADELPHIA, PA 19104 (4) CHILDREN'S HOSPITAL 23-1352166 30,000 FΜV N/A MEDICAL OF PHILA 34TH-CIVIC RESEARCH CENTER BLVD PHILADELPHIA, PA 19104 N/A (5) UNIV OF MICHIGAN 38-6006309 30,000 FΜV MEDICAL 1150 W MED CTR DR RESEARCH ANN ARBOR, MI 48109

rt III	Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990,	Part IV, line 22
	Use Schedule I-1 (Form 990) if additional space is needed.	

(a)Type of grant or assistance	(b) Number of recipients	(c) A mount of cash grant	(d)A mount of non-cash assistance	(e)Method of valuation (book, FMV, appraisal, other)	(f)Description of non-cash assistance
(1) INSURANCE PREMIUM CO- PAYMENTS	4500	8,713,825		FMV	N/A

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

Ident if ier

Return Reference

Explanation

Schedule I (Form 990) 2010

DLN: 93493208011551

Employer identification number

OMB No 1545-0047

Schedule J (Form 990)

Department of the Treasury Internal Revenue Service

Name of the organization

Compensation Information For certain Officers, Directors, Trustees, Key Employees, and Highest

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

► Attach to Form 990. ► See separate instructions.

Open to Public Inspection

NA	TIONAL ORGANIZATION FOR RARE DISORDERS INC				
		13-3223946			
Pa	rt I Questions Regarding Compensati	on			
				Yes	No
1a		rovided any of the following to or for a person listed in Form II to provide any relevant information regarding these items			
	First-class or charter travel	Housing allowance or residence for personal use			
	Travel for companions	Payments for business use of personal residence			
	Tax idemnification and gross-up payments	Health or social club dues or initiation fees			
	Discretionary spending account	Personal services (e g , maid, chauffeur, chef)			
b	·	organization follow a written policy regarding payment or scribed above? If "No," complete Part III to explain	1b		
2	Did the organization require substantiation prior to officers, directors, trustees, and the CEO/Executive	o reimbursing or allowing expenses incurred by all ve Director, regarding the items checked in line 1a?	2		
3	Indicate which, if any, of the following the organiza organization's CEO/Executive Director Check all	that apply			
	Compensation committee	Written employment contract			
	Independent compensation consultant	Compensation survey or study			
	Form 990 of other organizations	Approval by the board or compensation committee			
4	During the year, did any person listed in Form 990 or a related organization	, Part VII, Section A , line ${ t 1a}$ with respect to the filing organization			
а	Receive a severance payment or change-of-contro	ol payment from the organization or a related organization?	4a		Νo
Ь	Participate in, or receive payment from, a supplem	nental nonqualified retirement plan?	4b		Νo
c	Participate in, or receive payment from, an equity-	based compensation arrangement?	4c		Νo
	If "Yes" to any of lines 4a-c, list the persons and	provide the applicable amounts for each item in Part III			
	Only 501(c)(3) and 501(c)(4) organizations only r	nust complete lines 5-9.			
5	For persons listed in form 990, Part VII, Section A compensation contingent on the revenues of	A, line 1a, did the organization pay or accrue any			
а	The organization?		5a		Νo
b	Any related organization?		5b		Νo
	If "Yes," to line 5a or 5b, describe in Part III				
6	For persons listed in form 990, Part VII, Section A compensation contingent on the net earnings of	A, line 1a, did the organization pay or accrue any			
а	The organization?		6a		Νo
b	Any related organization?		6b		Νo
	If "Yes," to line 6a or 6b, describe in Part III				
7	For persons listed in Form 990, Part VII, Section payments not described in lines 5 and 6? If "Yes,"	A , line 1a, did the organization provide any non-fixed ' describe in Part III	7		No
8	Were any amounts reported in Form 990, Part VII subject to the initial contract exception described	, paid or accured pursuant to a contract that was in Regs section 53 4958-4(a)(3)? If "Yes," describe			
	ın Part III		8		Νo
9	If "Yes" to line 8, did the organization also follow t section 53 4958-6(c)?	he rebuttable presumption procedure described in Regulations	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)(1)-(111) must equal the applicable column (D) or column (E) amounts on Form 990, Part VII, line 1a

(A) Name		(B) Breakdown of	W-2 and/or 1099-MI		(C) Retirement and	(D) Nontaxable	(E) Total of columns	(F) Compensation
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	other deferred compensation	benefits	(B)(ı)-(D)	reported in prior Form 990 or Form 990-EZ
(1) PETER	(1)							228,906
SALTONSTALL	(11)	244,823					244,823	
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								
(10)								
(11)								
(12)								
(13)								
(14)								
(15)								
(16)								
		•		•	•		•	

Schedule J (Form 990) 2010 Page **3**

Part III Supplemental Information

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

Identifier Return Reference Explanation

Schedule J (Form 990) 2010

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DLN: 93493208011551

OMB No 1545-0047

2010

Open to Public Inspection

Supplemental Information to Form 990 or 990-EZ

Department of the Treasury
Internal Revenue Service

EZ)

SCHEDULE 0

(Form 990 or 990-

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.

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS INC Employer identification number

13-3223946

ldentifier	Return Reference	Explanation
Form 990 XI	5	UNREALIZED GAINS LOSSES ON BOOKS NOT ON FORM 990

Identifier	Return Reference	Explanation
Form 990 V I	11	REVIEWED BY CFO, CEO, TREASURER, FINANCE COMMITTEE, EXECUTIVE COMMITTEE AND CHAIRPERSON OF THE AUDIT COMMITTEE PRIOR TO BEING FILED

ldentifier	Return Reference	Explanation
Form 990 VI	12	BOD REVIEWS ALL CONFLICT OF INTEREST MATTERS AND DOCUMENTS WHEN APPROPRIATE

Identifier	Return Reference	Explanation
Form 990 VI	15	BOD REVIEWS THIRD PARTY INFO AS WELL AS PUBLISHED SALARY RANGES

ldentifier	Return Reference	Explanation
Form 990 V I	19	GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST FINANCIAL STATEMENTS ARE POSTED ON NORDS WEBSITE

ldentifier	Return Reference	Explanation
Form 990		SEE ATTACHED LIST FOR ALL STATES WHERE FORM 990 IS FILED

ldentifier	Return Reference	Explanation								
Form 990 Part III Program Service Accomplishments	Line 4d Other Activities	Program Service Expenses 144,881, Grants and allocations 0, Revenue 0 TECHNICAL ASSISTANCE-PROVIDE ASSISTANCE TO VOLUNTARY HEALTH AGENCIES AND SUPPORT GROUPS TO IMPROVE THEIR EFFECTIVENESS, COMPLIANCE WITH NON-PROFIT STANDARDS AND PROGRAM DEVELOPMENT								

ldentifier	Return Reference	Explanation									
Form 990 Part III Program Service Accomplishments	Line 4d Other Activities	Program Service Expenses 334,468, Grants and allocations 0, Revenue 0 RESEARCH-PROVIDES ASSISTANCE THROUGH FUNDING OF VARIOUS RESEARCH GRANTS TO ACADEMIC SCIENTISTS DEVELOPING NEW TREATMENTS AND DIAGNOSTICS FOR RARE DISORDERS									

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DLN: 93493208011551

OMB No 1545-0172

Form **4562**

Depreciation and Amortization (Including Information on Listed Property)

Department of the Treasury Internal Revenue Service (99)

See separate instructions.

► Attach to your tax return.

Attachment Sequence No 67

Name(s) shown on return NATIONAL ORGANIZATI INC	Business or activity to which this form relates							Identifying number			
	To Expense (m n l o	to Dart I			
1 Maximum amount See	ou have any li					u con	прте	te Part I.	1	500,000	
	—										
2 Total cost of section 1	2	138,479									
3 Threshold cost of sect	3	2,000,000									
4 Reduction in limitation				·		•			4		
5 Dollar limitation for tax		line 4 from line	e 1 Ifzero	or less, enter - (O-Ifm	narried	filin	g	l _		
separately, see instruc	tions				• •	•			5	500,000	
6 (a)		(b) Cost (business use only)					ost	_			
							+			_	
7 Listed property Enter	the amount from	line 29 .				7					
8 Total elected cost of s	ection 179 prop	erty Addamo	unts ın colu	ımn (c), lınes 6	and 7				8		
9 Tentative deduction E	nter the smaller	of line 5 or lin	e 8 .						. 9		
10 Carryover of disallowed	d deduction from	ı lıne 13 of you	ır 2009 For	m 4562 .					10		
11 Business income limitation	Enter the smaller of	business income	(not less than	n zero) or line 5 (se	ee instru	ctions)			11		
11 Business income limitation Enter the smaller of business income (not less than zero) or line 5 (see instructions)											
13 Carryover of disallowed		•			. 🕨	13	Т		12		
Note: Do not use Part					se Pai						
							t inc	lude listed n	roperi	:y) (See instructions)	
14 Special depreciation al										, , (see matractions)	
tax year (see instruction		,	•		, ,			Ū	14		
15 Property subject to see	15										
16 Other depreciation (inc	luding ACRS)								16	25,672	
Part IIII MACRS De	preciation (I	Do not inclu	de listed p	property.) (Se	e inst	ructio	ns.)				
			Se	ction A						_	
17 MACRS deductions for	assets placed ı	n service in ta	x years beg	ginning before 2	010	•			17	58,300	
18 If you are electing to general asset account		•		e during the t	ax yea	ar into	o on	e or more ⊳ Γ			
Section B-Asse					Using	, the	Ge	neral Dep	recia	ation System	
		(c) Basi			T .					•	
(a) Classification of property	(b) Month and year placed in service	deprecia (business/in use only—see ins	vestment	(d) Recovery period	(e) C	onven	tıon	(f) Metho	od	(g) Depreciation deduction	
19a 3-year property											
b 5-year property											
c 7 - year property											
d 10-year property											
e 15-year property											
f 20-year property	-										
g 25-year property				25 yrs	<u> </u>			S/L			
h Residential rental				27 5 yrs	+	м м		S/L			
property				27 5 yrs	+	MM		S/L			
i Nonresidential real property				39 yrs	M M M M		S/L S/L				
	n C—Assets Plac	ced in Service	During 2010	Tay Vear Hein			at ive		n Svet	em .	
20a Class life	C ASSECT FIELD	Service	Darling 2010	Tax Tear oain		ittiid		S/L	1 3 9 3 6		
b 12-year	-			12 yrs	 			S/L			
c 40-year				40 yrs		ММ		S/L			
	y (see instruc	tions)						, –			
21 Listed property Enter									21		
22 Total. Add amounts fro								Enter here	22	83,972	
23 For assets shown abov portion of the basis att	•	_			e <u> </u>	23					

Part V

Listed Property (Include automobiles, certain other vehicles, certain computers, and property used for entertainment, recreation, or amusement.)

Note: For any vehicle for which you are using the standard mileage rate or deducting lease expense, complete **only** 24a, 24b, columns (a) through (c) of Section A, all of Section B, and Section C if applicable.

		z+a, $z+b$, cc														
Section A—Depre	ciation a	<u>nd Other Ir</u>	<u>ıforma</u>	tion (C	aution	: See	the i	<u>nstru</u>	ctic	ons for I	imits i	for pa	sseng _'	<u>er au</u>	<u>tomot</u>	oiles. 🕽
24a Do you have evider	ice to support i	the business/inv	estment u	ise claimed	d? ┌Yes	Гио			24b	If "Yes,"	s the ev	dence	written?	$\Gamma_{Y\epsilon}$	ᇙᄃᇄ	0
(a) Type of property (list vehicles first)	(b) Business/ (d) Date placed in service use percentage			rother (husiness/investment			(f) Recove period	'	(g) Method/ Conventio		(h) Depreciation/ deduction			(i) Elected section 179 cost		
25Special depreciation allo	•		rty placed	ın service o	during the	tax year	and u	ısed m	ore t	han 25						
26 Property used more	than 50%	n a qualified l	business	use						· ·						
		%							Т					\top		
		%												\perp		
37 Dramarty used EON		%														
27 Property used 50%	or less in a	quanned bus	mess us	e	1			l	S	/L -	Т			$\overline{}$		
		%							_	/L -				1		
		%							S	/L -				그		
28 Add amounts in co	olumn (h), lır	nes 25 throug	h 27 En	ter here a	and on Iir	ne 21,	page	1	•	28						
29 Add amounts in co	olumn (ı), lın	e 26 Enterhe	ere and c	n line 7,	page 1					•		29				
				—Infor												
Complete this section If you provided vehicles to														se vehic	les	
· ·					a)	T	b)			c)		1)	(e	_		f)
30 Total business/investment miles driven during the year (do not include commuting miles)				Vehi	Vehi	Vehicle 2		Vehicle 3		, ,		, , ,		- 1		
31 Total commuting r	miles driven	during the ye	ar .													
32 Total other persor	nal(noncomm	nuting) miles (driven													
33 Total miles driven during the year Add lines 30 through 32																
34 Was the vehicle a		ersonal use		Yes	No	Yes	No	Y	es	No	Yes	No	Yes	No	Yes	No
during off-duty ho	urs? .															
35 Was the vehicle us owner or related p		by a more th	an 5%													
36 Is another vehicle	available fo	r personal us	e? .													
Section Answer these question 5% owners or related	ns to determ	•	et an exc												not mo	re thar
37 Do you maintain a	written polic	y statement	that prob	nibits all	personal	use of	vehi	cles,	nclu	udıng cor	nmutın	g, by y	our	Y	es	No
employees? .						•	٠	•	•			•	•			
38 Do you maintain a employees? See the																
39 Do you treat all us	e of vehicles	s by employee	es as pei	sonal us	e? .											
40 Do you provide movehicles, and retain				oyees, ol	otain info	rmatio	n fror	m you	ren	nployees	about	the us	e of the	e 🗀		
41 Do you meet the re				• • automobi	e demor	• nstratio	n us	e? (Se	e ir	nstructio	ns)					
Note: If your answ	er to 37, 38	, 39, 40, or 4	1 is "Ye:	s," do not	t comple	te Sect	ion B	3 for t	ne c	overed v	ehicles	5				
Part VI Amo	rtization															
(b) Date			(c) A mortizable			((d) ·			e) cization A mor			(f) rtızatıon for			
Description of costs amortization begins						ection period or percentage				this year						
42 A mortization of co	sts that beg	ıns durıng yo	ur 2010	tax year	(see inst	truction	ıs)			-						
43 A mortization of co	sts that beg	an before you	r 2010 t	ax year							43					
	_	-									—					

44 Total. Add amounts in column (f) See the instructions for where to report

44