

Form **990**

Return of Organization Exempt From Income Tax
Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

OMB No. 1545-0047

2021

Department of the Treasury
Internal Revenue Service

▶ Do not enter social security numbers on this form as it may be made public.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Open to Public Inspection

A For the 2021 calendar year, or tax year beginning and ending

| | | |
|--|--|---|
| B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending | C Name of organization NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. Doing business as _____ Number and street (or P.O. box if mail is not delivered to street address) Room/suite 1900 CROWN COLONY DR., 3RD FL. 310 City or town, state or province, country, and ZIP or foreign postal code QUINCY, MA 02169 F Name and address of principal officer: VINCENT J. MURPHY, JR. SAME AS C ABOVE | D Employer identification number 13-3223946 E Telephone number 617-249-7300 G Gross receipts \$ 47,982,879. H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions H(c) Group exemption number ▶ |
| I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527 | | |
| J Website: ▶ WWW.RAREDISEASES.ORG | | |
| K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶ | | |
| L Year of formation: 1983 | | M State of legal domicile: NY |

Part I Summary

| | | | |
|------------|---|----------------------------------|---------------------|
| 1 | Briefly describe the organization's mission or most significant activities: NORD STRIVES TO IMPROVE THE LIVES OF THOSE WITH RARE DISEASES THROUGH ASSISTANCE PROGRAMS, | | |
| 2 | Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets. | | |
| 3 | Number of voting members of the governing body (Part VI, line 1a) | 3 | 12 |
| 4 | Number of independent voting members of the governing body (Part VI, line 1b) | 4 | 11 |
| 5 | Total number of individuals employed in calendar year 2021 (Part V, line 2a) | 5 | 111 |
| 6 | Total number of volunteers (estimate if necessary) | 6 | 306 |
| 7a | Total unrelated business revenue from Part VIII, column (C), line 12 | 7a | 0. |
| 7b | Net unrelated business taxable income from Form 990-T, Part I, line 11 | 7b | 0. |
| 8 | Contributions and grants (Part VIII, line 1h) | Prior Year | Current Year |
| 9 | Program service revenue (Part VIII, line 2g) | 36,711,628. | 36,679,921. |
| 10 | Investment income (Part VIII, column (A), lines 3, 4, and 7d) | 5,782,111. | 6,266,078. |
| 11 | Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) | 349,621. | 242,173. |
| 12 | Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) | 0. | 0. |
| 13 | Grants and similar amounts paid (Part IX, column (A), lines 1-3) | 42,843,360. | 43,188,172. |
| 14 | Benefits paid to or for members (Part IX, column (A), line 4) | 40,732,238. | 44,198,311. |
| 15 | Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) | 0. | 0. |
| 16a | Professional fundraising fees (Part IX, column (A), line 11e) | 8,470,391. | 10,006,667. |
| 16b | Total fundraising expenses (Part IX, column (D), line 25) ▶ 1,694,897. | 0. | 0. |
| 17 | Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) | 3,509,490. | 3,515,539. |
| 18 | Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) | 52,712,119. | 57,720,517. |
| 19 | Revenue less expenses. Subtract line 18 from line 12 | -9,868,759. | -14,532,345. |
| 20 | Total assets (Part X, line 16) | Beginning of Current Year | End of Year |
| 21 | Total liabilities (Part X, line 26) | 52,774,540. | 37,875,246. |
| 22 | Net assets or fund balances. Subtract line 21 from line 20 | 3,206,888. | 2,933,549. |
| | | 49,567,652. | 34,941,697. |

Part II Signature Block

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

| | | |
|-------------------------------|--|---------------|
| Sign Here | Signature of officer _____ VINCENT J. MURPHY, JR., VICE PRESIDENT OF FINANCE Type or print name and title | Date _____ |
| Paid Preparer Use Only | Print/Type preparer's name COURTNEY MCFARLAND, CPA Preparer's signature COURTNEY MCFARLAND, CPA Date 09/22/22 Check if self-employed <input type="checkbox"/> PTIN P01645518 Firm's name ▶ AAFCPAS, INC. Firm's address ▶ 50 WASHINGTON STREET WESTBOROUGH, MA 01581 Firm's EIN ▶ 04-2571780 Phone no. 508-366-9100 | |

May the IRS discuss this return with the preparer shown above? See instructions Yes No

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission:
NORD LEADS THE FIGHT TO IMPROVE THE LIVES OF PEOPLE AFFECTED BY RARE DISEASES THROUGH EDUCATION, PATIENT ASSISTANCE PROGRAMS, ADVOCACY, AND BY PROMOTING RESEARCH.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [X] Yes [] No
If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [] Yes [X] No
If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 46,631,923. including grants of \$ 44,198,311.) (Revenue \$ 3,515,821.)
PATIENT ASSISTANCE PROGRAMS PROVIDE FINANCIAL ASSISTANCE TO HELP ELIGIBLE PATIENTS ACCESS LIFESAVING THERAPIES AND SERVICES PRESCRIBED BY THEIR PHYSICIANS. IN 2021 NORD PROVIDED FINANCIAL ASSISTANCE TO 9,178 PEOPLE WITH RARE DISEASES. IN ADDITION, NORD WORKS WITH ORGANIZATIONS CONDUCTING CLINICAL TRIALS OF NEW TREATMENTS IN ARRANGING FOR PATIENTS WITH RARE DISEASES AND FAMILY MEMBERS TO TRAVEL TO THE SITES WHERE THE TRIALS ARE BEING CONDUCTED. IN 2021, THERE WERE 145 PATIENTS THAT NORD ASSISTED AS PART OF THAT SPECIAL CLINICAL TRIAL TRAVEL ASSISTANCE PROGRAM.

4b (Code:) (Expenses \$ 1,334,793. including grants of \$) (Revenue \$)
NORD'S ADVOCACY EFFORTS ARE FOCUSED ON SERVING AS A LIAISON BETWEEN THE RARE DISEASE COMMUNITY AND THE VARIOUS ORGANIZATIONS AND INSTITUTIONS THAT HAVE A DIRECT IMPACT ON THE LIVES OF THE 30 MILLION AMERICANS LIVING WITH RARE DISEASES. NORD ENGAGES ALL TYPES OF ORGANZIATIONS, INCLUDING STATE AND FEDERAL AGENCIES AND LEGISLATORS, OTHER NON-PROFIT ORGANIZATIONS, AND FOR-PROFIT ORGANIZATIONS TO HELP RAISE AWARENESS AROUND THE NEEDS OF RARE DISEASE PATIENTS AND TO COLLECTIVELY CONTRIBUTE TO REALIZING SOLUTIONS POSITIVELY IMPACT THE DIVERSE RARE DISEASE COMMUNITY.

4c (Code:) (Expenses \$ 2,874,375. including grants of \$) (Revenue \$ 703,522.)
IN 2021, NORD HAS CONTINUED TO DEVELOP ITS NATURAL HISTORY/REGISTRY PLATFORM TO HELP RESEARCHERS BETTER UNDERSTAND THE PATIENT EXPERIENCE AND PROMOTE DEVELOPMENT OF INNOVATIVE, SAFE AND EFFECTIVE THERAPIES. AS OF DECEMBER 31, 2021, THERE WERE 12,344 PARTICIPANTS ACROSS 29 DISEASE-SPECIFIC DATABASES AS PART OF NORD'S REGISTRY PROGRAM.

4d Other program services (Describe on Schedule O.)
(Expenses \$ 1,984,708. including grants of \$) (Revenue \$ 2,046,735.)

4e Total program service expenses 52,825,799.

Part IV Checklist of Required Schedules

| | Yes | No |
|---|-----|----|
| 1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i> | X | |
| 2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions | X | |
| 3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i> | | X |
| 4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i> | X | |
| 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 Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i> | | X |
| 6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i> | | X |
| 7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i> | | X |
| 8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i> | | X |
| 9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i> | | X |
| 10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V</i> | X | |
| 11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable. | | |
| a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i> | X | |
| 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? <i>If "Yes," complete Schedule D, Part VII</i> | | X |
| 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? <i>If "Yes," complete Schedule D, Part VIII</i> | | X |
| 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? <i>If "Yes," complete Schedule D, Part IX</i> | | X |
| e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> | X | |
| 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)? <i>If "Yes," complete Schedule D, Part X</i> | X | |
| 12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i> | X | |
| b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i> | | X |
| 13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> | | X |
| 14a Did the organization maintain an office, employees, or agents outside of the United States? | | X |
| b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i> | | X |
| 15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i> | X | |
| 16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i> | | X |
| 17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I.</i> See instructions | | X |
| 18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i> | | X |
| 19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i> | | X |
| 20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> | | X |
| b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? | | |
| 21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> | X | |

Part IV Checklist of Required Schedules (continued)

| | Yes | No |
|---|-----|----|
| 22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i> | X | |
| 23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i> | X | |
| 24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> | | X |
| b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? | | |
| 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? | | |
| d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? | | |
| 25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i> | | X |
| b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i> | | X |
| 26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i> | | X |
| 27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> | | X |
| 28 Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions): | | |
| a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i> | | X |
| b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i> | | X |
| c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i> | | X |
| 29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> | | X |
| 30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i> | | X |
| 31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> | | X |
| 32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i> | | X |
| 33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i> | | X |
| 34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i> | | X |
| 35a Did the organization have a controlled entity within the meaning of section 512(b)(13)? | | X |
| b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i> | | |
| 36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i> | | X |
| 37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i> | | X |
| 38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? | X | |

Note: All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

| | Yes | No |
|---|-----|----|
| 1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable | | |
| b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable | | |
| c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? | X | |

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

| | | Yes | No |
|--|--|-----|----|
| 2a | Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return 2a 111 | | |
| b | If at least one is reported on line 2a, did the organization file all required federal employment tax returns? 2b X | X | |
| 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? 3a | | X |
| b | If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O 3b | | |
| 4a | At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? 4a | | X |
| b | If "Yes," enter the name of the foreign country ▶ _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR). | | |
| 5a | Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? 5a | | X |
| b | Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? 5b | | X |
| c | If "Yes" to line 5a or 5b, did the organization file Form 8886-T? 5c | | |
| 6a | Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? 6a | | X |
| b | If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? 6b | | |
| 7 | Organizations that may receive deductible contributions under section 170(c). | | |
| a | Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor? 7a | | X |
| b | If "Yes," did the organization notify the donor of the value of the goods or services provided? 7b | | |
| c | Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? 7c | | X |
| d | If "Yes," indicate the number of Forms 8282 filed during the year 7d | | |
| e | Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? 7e | | X |
| f | Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? 7f | | X |
| g | 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. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year? 8 | | |
| 9 | Sponsoring organizations maintaining donor advised funds. | | |
| a | Did the sponsoring organization make any taxable distributions under section 4966? 9a | | |
| b | Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? 9b | | |
| 10 | Section 501(c)(7) organizations. Enter: | | |
| a | Initiation fees and capital contributions included on Part VIII, line 12 10a | | |
| b | Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b | | |
| 11 | Section 501(c)(12) organizations. Enter: | | |
| a | Gross income from members or shareholders 11a | | |
| b | Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.) 11b | | |
| 12a | Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? 12a | | |
| b | If "Yes," enter the amount of tax-exempt interest received or accrued during the year 12b | | |
| 13 | Section 501(c)(29) qualified nonprofit health insurance issuers. | | |
| a | Is the organization licensed to issue qualified health plans in more than one state? 13a | | |
| Note: See the instructions for additional information the organization must report on Schedule O. | | | |
| b | 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 13b | | |
| c | Enter the amount of reserves on hand 13c | | |
| 14a | Did the organization receive any payments for indoor tanning services during the tax year? 14a | | X |
| b | If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O 14b | | |
| 15 | Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? 15 | | X |
| If "Yes," see the instructions and file Form 4720, Schedule N. | | | |
| 16 | Is the organization an educational institution subject to the section 4968 excise tax on net investment income? 16 | | X |
| If "Yes," complete Form 4720, Schedule O. | | | |
| 17 | Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? 17 | | |
| If "Yes," complete Form 6069. | | | |

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions.

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

Section A. Governing Body and Management

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

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

| | | Yes | No |
|------------|--|-----|----|
| 10a | Did the organization have local chapters, branches, or affiliates? | X | |
| 10b | If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? | X | |
| 11a | Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? | X | |
| 11b | Describe on Schedule O the process, if any, used by the organization to review this Form 990. | | |
| 12a | Did the organization have a written conflict of interest policy? If "No," go to line 13 | X | |
| 12b | Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? | X | |
| 12c | Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done | X | |
| 13 | Did the organization have a written whistleblower policy? | X | |
| 14 | Did the organization have a written document retention and destruction policy? | X | |
| 15 | Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? | | |
| 15a | The organization's CEO, Executive Director, or top management official | X | |
| 15b | Other officers or key employees of the organization | X | |
| | If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. | | |
| 16a | Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? | | X |
| 16b | If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? | | |

Section C. Disclosure

- 17** List the states with which a copy of this Form 990 is required to be filed **▶** CT, NY, AL, CA, FL, GA, IL, KS, KY, MA, MD, MI
- 18** Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
 Own website Another's website Upon request Other (explain on Schedule O)
- 19** Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20** State the name, address, and telephone number of the person who possesses the organization's books and records **▶**
 VINCENT MURPHY - 617-249-7300
 1900 CROWN COLONY DRIVE, 3RD FLOOR, QUINCY, MA 02169

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See the 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, Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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. See the instructions for the order in which to list the persons above.

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

| (A) Name and title | (B) Average hours per week (list any hours for related organizations below line) | (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) | | | | | | (D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC) | (E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC) | (F) Estimated amount of other compensation from the organization and related organizations |
|---|---|---|-----------------------|---------|--------------|------------------------------|----------|---|--|---|
| | | Individual trustee or director | Institutional trustee | Officer | Key employee | Highest compensated employee | Former | | | |
| (1) PETER SALTONSTALL PRESIDENT/CEO | 35.00 | X | | X | | | 452,672. | 0. | 36,275. | |
| (2) PAMELA GAVIN CHIEF OPERATING OFFICER | 35.00 | | | X | | | 345,320. | 0. | 20,504. | |
| (3) PRASHANT GOEL VP INFORMATION TECHNOLOGY | 35.00 | | | | X | | 258,821. | 0. | 14,808. | |
| (4) ALEXA MOORE VP OF DEVELOPMENT | 35.00 | | | | X | | 218,063. | 0. | 45,061. | |
| (5) RACHEL SHER VP POLICY & REGULATORY AFFAIRS | 35.00 | | | | X | | 225,960. | 0. | 20,612. | |
| (6) EDWARD NEILAN CHIEF MEDICAL & SCIENTIFIC OFFICER | 35.00 | | | | X | | 180,810. | 0. | 29,583. | |
| (7) VINCENT J. MURPHY, JR. VP FINANCE | 35.00 | | | X | | | 129,355. | 0. | 41,850. | |
| (8) JILL POLLANDER VP PATIENT SERVICES | 35.00 | | | | X | | 139,242. | 0. | 29,723. | |
| (9) KATHLEEN HOLCOMBE CHAIR | 10.00 | X | | X | | | 0. | 0. | 0. | |
| (10) STEVEN GROSSMAN SECRETARY | 8.00 | X | | X | | | 0. | 0. | 0. | |
| (11) FREDERICK BARR, MD DIRECTOR | 1.00 | X | | | | | 0. | 0. | 0. | |
| (12) RONALD J. BARTEK DIRECTOR | 5.00 | X | | | | | 0. | 0. | 0. | |
| (13) SUSAN HEDSTROM DIRECTOR | 2.00 | X | | | | | 0. | 0. | 0. | |
| (14) JIM PALMA DIRECTOR | 3.00 | X | | | | | 0. | 0. | 0. | |
| (15) SUSAN BERRY, MD DIRECTOR | 2.00 | X | | | | | 0. | 0. | 0. | |
| (16) SHAFALI JESTE, MD DIRECTOR | 1.00 | X | | | | | 0. | 0. | 0. | |
| (17) PHILLIP PEARL, MD DIRECTOR | 2.00 | X | | | | | 0. | 0. | 0. | |

Part VIII Statement of Revenue

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

| | | | (A) | (B) | (C) | (D) | |
|---|---|----------------------|----------------|------------------------------------|----------------------------|--|--|
| | | | Total revenue | Related or exempt function revenue | Unrelated business revenue | Revenue excluded from tax under sections 512 - 514 | |
| Contributions, Gifts, Grants and Other Similar Amounts | 1 a Federated campaigns | 1a | | | | | |
| | b Membership dues | 1b | 1,828,085. | | | | |
| | 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 | 1f | 34,851,836. | | | | |
| | g Noncash contributions included in lines 1a-1f | 1g | \$ | | | | |
| | h Total. Add lines 1a-1f | | | 36,679,921. | | | |
| Program Service Revenue | 2 a PATIENT ASSISTANCE FEE | Business Code | 624100 | 3,470,944. | 3,470,944. | | |
| | b PROGRAMMATIC EVENTS AN | | 624100 | 1,707,001. | 1,707,001. | | |
| | c REGISTRY, WEB SUBSCRIP | | 624100 | 1,000,570. | 1,000,570. | | |
| | d DRUG, TRAVEL AND LODGI | | 624100 | 44,877. | 44,877. | | |
| | e RESEARCH FEES | | 624100 | 42,686. | 42,686. | | |
| | f All other program service revenue | | | | | | |
| | g Total. Add lines 2a-2f | | | 6,266,078. | | | |
| Other Revenue | 3 Investment income (including dividends, interest, and other similar amounts) | | | 223,148. | | 223,148. | |
| | 4 Income from investment of tax-exempt bond proceeds | | | | | | |
| | 5 Royalties | | | | | | |
| | 6 a Gross rents | 6a | (i) Real | | | | |
| | | | (ii) Personal | | | | |
| | | | | | | | |
| | b Less: rental expenses | 6b | | | | | |
| | c Rental income or (loss) | 6c | | | | | |
| | d Net rental income or (loss) | | | | | | |
| | 7 a Gross amount from sales of assets other than inventory | 7a | (i) Securities | | 4,813,732. | | |
| | | | (ii) Other | | | | |
| | | | | | | | |
| | b Less: cost or other basis and sales expenses | 7b | | 4,794,707. | | | |
| | c Gain or (loss) | 7c | | 19,025. | | | |
| d Net gain or (loss) | | | 19,025. | | 19,025. | | |
| 8 a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18 | 8a | | | | | | |
| | | | | | | | |
| | | | | | | | |
| b Less: direct expenses | 8b | | | | | | |
| c Net income or (loss) from fundraising events | | | | | | | |
| 9 a Gross income from gaming activities. See Part IV, line 19 | 9a | | | | | | |
| | | | | | | | |
| | | | | | | | |
| b Less: direct expenses | 9b | | | | | | |
| c Net income or (loss) from gaming activities | | | | | | | |
| 10 a Gross sales of inventory, less returns and allowances | 10a | | | | | | |
| | | | | | | | |
| | | | | | | | |
| b Less: cost of goods sold | 10b | | | | | | |
| c Net income or (loss) from sales of inventory | | | | | | | |
| Miscellaneous Revenue | 11 a _____ | Business Code | | | | | |
| | b _____ | | | | | | |
| | c _____ | | | | | | |
| | d All other revenue | | | | | | |
| | e Total. Add lines 11a-11d | | | | | | |
| 12 Total revenue. See instructions | | | 43,188,172. | 6,266,078. | 0. | 242,173. | |

Part IX Statement of Functional Expenses

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

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

| Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII. | (A) Total expenses | (B) Program service expenses | (C) Management and general expenses | (D) Fundraising expenses |
|--|-----------------------|---------------------------------|--|-----------------------------|
| 1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 | 420,936. | 420,936. | | |
| 2 Grants and other assistance to domestic individuals. See Part IV, line 22 | 43,634,227. | 43,634,227. | | |
| 3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 | 143,148. | 143,148. | | |
| 4 Benefits paid to or for members | | | | |
| 5 Compensation of current officers, directors, trustees, and key employees | 1,025,976. | 536,955. | 366,784. | 122,237. |
| 6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) | | | | |
| 7 Other salaries and wages | 7,234,869. | 4,737,559. | 1,511,370. | 985,940. |
| 8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) | 201,106. | 135,124. | 38,612. | 27,370. |
| 9 Other employee benefits | 994,723. | 832,192. | 37,942. | 124,589. |
| 10 Payroll taxes | 549,993. | 302,828. | 167,853. | 79,312. |
| 11 Fees for services (nonemployees): | | | | |
| a Management | | | | |
| b Legal | 279,105. | 117,028. | 145,766. | 16,311. |
| c Accounting | 54,207. | | 54,207. | |
| d Lobbying | 172,678. | 172,678. | | |
| e Professional fundraising services. See Part IV, line 17 | | | | |
| f Investment management fees | 61,515. | | 61,515. | |
| g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.) | 602,203. | 547,754. | 30,619. | 23,830. |
| 12 Advertising and promotion | | | | |
| 13 Office expenses | | | | |
| 14 Information technology | 487,430. | 122,709. | 322,189. | 42,532. |
| 15 Royalties | | | | |
| 16 Occupancy | 497,517. | 216,176. | 216,777. | 64,564. |
| 17 Travel | 2,284. | 490. | | 1,794. |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials | | | | |
| 19 Conferences, conventions, and meetings | 433,971. | 264,562. | 2,019. | 167,390. |
| 20 Interest | | | | |
| 21 Payments to affiliates | | | | |
| 22 Depreciation, depletion, and amortization | 457,604. | 426,512. | 23,015. | 8,077. |
| 23 Insurance | | | | |
| 24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.) | | | | |
| a MISCELLANEOUS | 467,025. | 214,921. | 221,153. | 30,951. |
| b | | | | |
| c | | | | |
| d | | | | |
| e All other expenses | | | | |
| 25 Total functional expenses. Add lines 1 through 24e | 57,720,517. | 52,825,799. | 3,199,821. | 1,694,897. |
| 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. | | | | |

Check here if following SOP 98-2 (ASC 958-720)

Part X Balance Sheet

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

| | | (A) | | (B) |
|---|--|-----------------------|-------------|-----------------------|
| | | Beginning of year | | End of year |
| Assets | 1 Cash - non-interest-bearing | 3,706,301. | 1 | 6,278,890. |
| | 2 Savings and temporary cash investments | 20,005,811. | 2 | 7,209,769. |
| | 3 Pledges and grants receivable, net | | 3 | |
| | 4 Accounts receivable, net | 1,358,053. | 4 | 1,240,510. |
| | 5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons | | 5 | |
| | 6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) | | 6 | |
| | 7 Notes and loans receivable, net | | 7 | |
| | 8 Inventories for sale or use | | 8 | |
| | 9 Prepaid expenses and deferred charges | 368,116. | 9 | 351,001. |
| | 10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D | 10a 4,965,462. | | |
| | b Less: accumulated depreciation | 10b 3,716,649. | 1,316,605. | 10c 1,248,813. |
| | 11 Investments - publicly traded securities | 25,721,504. | 11 | 21,200,029. |
| | 12 Investments - other securities. See Part IV, line 11 | | 12 | |
| | 13 Investments - program-related. See Part IV, line 11 | | 13 | |
| | 14 Intangible assets | 109,919. | 14 | 74,147. |
| | 15 Other assets. See Part IV, line 11 | 188,231. | 15 | 272,087. |
| 16 Total assets. Add lines 1 through 15 (must equal line 33) | 52,774,540. | 16 | 37,875,246. | |
| Liabilities | 17 Accounts payable and accrued expenses | 1,250,334. | 17 | 1,435,985. |
| | 18 Grants payable | 1,363,220. | 18 | 942,285. |
| | 19 Deferred revenue | 248,181. | 19 | 242,900. |
| | 20 Tax-exempt bond liabilities | | 20 | |
| | 21 Escrow or custodial account liability. Complete Part IV of Schedule D | | 21 | |
| | 22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons | | 22 | |
| | 23 Secured mortgages and notes payable to unrelated third parties | 236,759. | 23 | 165,080. |
| | 24 Unsecured notes and loans payable to unrelated third parties | | 24 | |
| | 25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D | 108,394. | 25 | 147,299. |
| | 26 Total liabilities. Add lines 17 through 25 | 3,206,888. | 26 | 2,933,549. |
| Net Assets or Fund Balances | Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33. | | | |
| | 27 Net assets without donor restrictions | 7,145,768. | 27 | 9,168,421. |
| | 28 Net assets with donor restrictions | 42,421,884. | 28 | 25,773,276. |
| | Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33. | | | |
| | 29 Capital stock or trust principal, or current funds | | 29 | |
| | 30 Paid-in or capital surplus, or land, building, or equipment fund | | 30 | |
| | 31 Retained earnings, endowment, accumulated income, or other funds | | 31 | |
| | 32 Total net assets or fund balances | 49,567,652. | 32 | 34,941,697. |
| 33 Total liabilities and net assets/fund balances | 52,774,540. | 33 | 37,875,246. | |

Form 990 (2021)

Part XI Reconciliation of Net Assets

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

| | | | |
|-----------|--|-----------|--------------|
| 1 | Total revenue (must equal Part VIII, column (A), line 12) | 1 | 43,188,172. |
| 2 | Total expenses (must equal Part IX, column (A), line 25) | 2 | 57,720,517. |
| 3 | Revenue less expenses. Subtract line 2 from line 1 | 3 | -14,532,345. |
| 4 | Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) | 4 | 49,567,652. |
| 5 | Net unrealized gains (losses) on investments | 5 | -93,610. |
| 6 | Donated services and use of facilities | 6 | |
| 7 | Investment expenses | 7 | |
| 8 | Prior period adjustments | 8 | |
| 9 | Other changes in net assets or fund balances (explain on Schedule O) | 9 | 0. |
| 10 | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B)) | 10 | 34,941,697. |

Part XII Financial Statements and Reporting

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

| | Yes | No |
|---|-----|----|
| 1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O. | | |
| 2a Were the organization's financial statements compiled or reviewed by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis | | X |
| b Were the organization's financial statements audited by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis | X | |
| c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? _____ If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O. | X | |
| 3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? _____ | X | |
| b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits _____ | X | |

Form 990 (2021)

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

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

| Calendar year (or fiscal year beginning in) ▶ | (a) 2017 | (b) 2018 | (c) 2019 | (d) 2020 | (e) 2021 | (f) Total |
|--|-------------|-------------|-------------|-------------|-------------|--------------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") | 48,281,104. | 42,070,943. | 43,644,020. | 36,711,628. | 36,851,836. | 207,559,531. |
| 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 | 48,281,104. | 42,070,943. | 43,644,020. | 36,711,628. | 36,851,836. | 207,559,531. |
| 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) | | | | | | 121,816,403. |
| 6 Public support. Subtract line 5 from line 4. | | | | | | 85,743,128. |

Section B. Total Support

| Calendar year (or fiscal year beginning in) ▶ | (a) 2017 | (b) 2018 | (c) 2019 | (d) 2020 | (e) 2021 | (f) Total |
|---|-------------|-------------|-------------|-------------|-------------|--------------------------|
| 7 Amounts from line 4 | 48,281,104. | 42,070,943. | 43,644,020. | 36,711,628. | 36,851,836. | 207,559,531. |
| 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources ... | 21,741. | 145,033. | 595,629. | 517,289. | 223,148. | 1,502,840. |
| 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 VI.) | | | | | | |
| 11 Total support. Add lines 7 through 10 | | | | | | 209,062,371. |
| 12 Gross receipts from related activities, etc. (see instructions) | | | | | 12 | 30,719,337. |
| 13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here | | | | | | <input type="checkbox"/> |

Section C. Computation of Public Support Percentage

| | | |
|---|-----------|-------------------------------------|
| 14 Public support percentage for 2021 (line 6, column (f), divided by line 11, column (f))..... | 14 | 41.01 % |
| 15 Public support percentage from 2020 Schedule A, Part II, line 14 | 15 | 41.66 % |
| 16a 33 1/3% support test - 2021. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization | | <input checked="" type="checkbox"/> |
| b 33 1/3% support test - 2020. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization | | <input type="checkbox"/> |
| 17a 10% -facts-and-circumstances test - 2021. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization | | <input type="checkbox"/> |
| b 10% -facts-and-circumstances test - 2020. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization | | <input type="checkbox"/> |
| 18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions | | <input type="checkbox"/> |

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

| Calendar year (or fiscal year beginning in) ► | (a) 2017 | (b) 2018 | (c) 2019 | (d) 2020 | (e) 2021 | (f) Total |
|---|----------|----------|----------|----------|----------|-----------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") | | | | | | |
| 2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose | | | | | | |
| 3 Gross receipts from activities that are not an unrelated trade or business under section 513 | | | | | | |
| 4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf | | | | | | |
| 5 The value of services or facilities furnished by a governmental unit to the organization without charge | | | | | | |
| 6 Total. Add lines 1 through 5 | | | | | | |
| 7a Amounts included on lines 1, 2, and 3 received from disqualified persons | | | | | | |
| b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year | | | | | | |
| c Add lines 7a and 7b | | | | | | |
| 8 Public support. (Subtract line 7c from line 6.) | | | | | | |

Section B. Total Support

| Calendar year (or fiscal year beginning in) ► | (a) 2017 | (b) 2018 | (c) 2019 | (d) 2020 | (e) 2021 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| 9 Amounts from line 6 | | | | | | |
| 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources | | | | | | |
| b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 | | | | | | |
| c Add lines 10a and 10b | | | | | | |
| 11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on | | | | | | |
| 12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) | | | | | | |
| 13 Total support. (Add lines 9, 10c, 11, and 12.) | | | | | | |

14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

Section C. Computation of Public Support Percentage

| | | |
|---|-----------|---|
| 15 Public support percentage for 2021 (line 8, column (f), divided by line 13, column (f)) | 15 | % |
| 16 Public support percentage from 2020 Schedule A, Part III, line 15 | 16 | % |

Section D. Computation of Investment Income Percentage

| | | |
|---|-----------|---|
| 17 Investment income percentage for 2021 (line 10c, column (f), divided by line 13, column (f)) | 17 | % |
| 18 Investment income percentage from 2020 Schedule A, Part III, line 17 | 18 | % |

19a 33 1/3% support tests - 2021. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2020. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV Supporting Organizations

(Complete only if you checked a box in line 12 on Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

| | Yes | No |
|--|-----|----|
| 1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i> | | |
| 2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i> | | |
| 3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i> | | |
| b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i> | | |
| c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i> | | |
| 4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i> | | |
| b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i> | | |
| c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i> | | |
| 5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i> | | |
| b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document? | | |
| c Substitutions only. Was the substitution the result of an event beyond the organization's control? | | |
| 6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i> | | |
| 7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990).</i> | | |
| 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i> | | |
| 9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i> | | |
| b Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i> | | |
| c Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i> | | |
| 10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i> | | |
| b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i> | | |

Part IV Supporting Organizations (continued)

| | Yes | No |
|--|-----|----|
| 11 Has the organization accepted a gift or contribution from any of the following persons? | | |
| a A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization? | | |
| b A family member of a person described on line 11a above? | | |
| c A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI. | | |
| 11a | | |
| 11b | | |
| 11c | | |

Section B. Type I Supporting Organizations

| | Yes | No |
|--|-----|----|
| 1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year. | | |
| 2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization. | | |
| 1 | | |
| 2 | | |

Section C. Type II Supporting Organizations

| | Yes | No |
|---|-----|----|
| 1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s). | | |
| 1 | | |

Section D. All Type III Supporting Organizations

| | Yes | No |
|---|-----|----|
| 1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided? | | |
| 2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s). | | |
| 3 By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard. | | |
| 1 | | |
| 2 | | |
| 3 | | |

Section E. Type III Functionally Integrated Supporting Organizations

| | | | |
|--|--|-----|----|
| 1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). | | | |
| a <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below. | | | |
| b <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below. | | | |
| c <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions). | | | |
| 2 Activities Test. Answer lines 2a and 2b below. | | | |
| a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities. | | Yes | No |
| b Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement. | | | |
| 3 Parent of Supported Organizations. Answer lines 3a and 3b below. | | | |
| a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI. | | | |
| b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard. | | | |
| 2a | | | |
| 2b | | | |
| 3a | | | |
| 3b | | | |

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

1 Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). See instructions.
All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

| Section A - Adjusted Net Income | | (A) Prior Year | (B) Current Year (optional) |
|---------------------------------|--|----------------|-----------------------------|
| 1 | Net short-term capital gain | 1 | |
| 2 | Recoveries of prior-year distributions | 2 | |
| 3 | Other gross income (see instructions) | 3 | |
| 4 | Add lines 1 through 3. | 4 | |
| 5 | Depreciation and depletion | 5 | |
| 6 | Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6 | |
| 7 | Other expenses (see instructions) | 7 | |
| 8 | Adjusted Net Income (subtract lines 5, 6, and 7 from line 4) | 8 | |

| Section B - Minimum Asset Amount | | (A) Prior Year | (B) Current Year (optional) |
|----------------------------------|---|----------------|-----------------------------|
| 1 | Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | | |
| a | Average monthly value of securities | 1a | |
| b | Average monthly cash balances | 1b | |
| c | Fair market value of other non-exempt-use assets | 1c | |
| d | Total (add lines 1a, 1b, and 1c) | 1d | |
| e | Discount claimed for blockage or other factors (explain in detail in Part VI): | | |
| 2 | Acquisition indebtedness applicable to non-exempt-use assets | 2 | |
| 3 | Subtract line 2 from line 1d. | 3 | |
| 4 | Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions). | 4 | |
| 5 | Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | |
| 6 | Multiply line 5 by 0.035. | 6 | |
| 7 | Recoveries of prior-year distributions | 7 | |
| 8 | Minimum Asset Amount (add line 7 to line 6) | 8 | |

| Section C - Distributable Amount | | | Current Year |
|----------------------------------|---|---|--------------|
| 1 | Adjusted net income for prior year (from Section A, line 8, column A) | 1 | |
| 2 | Enter 0.85 of line 1. | 2 | |
| 3 | Minimum asset amount for prior year (from Section B, line 8, column A) | 3 | |
| 4 | Enter greater of line 2 or line 3. | 4 | |
| 5 | Income tax imposed in prior year | 5 | |
| 6 | Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions). | 6 | |
| 7 | <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions). | | |

Schedule A (Form 990) 2021

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

| Section D - Distributions | | Current Year |
|---------------------------|--|--------------|
| 1 | Amounts paid to supported organizations to accomplish exempt purposes | 1 |
| 2 | Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity | 2 |
| 3 | Administrative expenses paid to accomplish exempt purposes of supported organizations | 3 |
| 4 | Amounts paid to acquire exempt-use assets | 4 |
| 5 | Qualified set-aside amounts (prior IRS approval required - provide details in Part VI) | 5 |
| 6 | Other distributions (describe in Part VI). See instructions. | 6 |
| 7 | Total annual distributions. Add lines 1 through 6. | 7 |
| 8 | Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions. | 8 |
| 9 | Distributable amount for 2021 from Section C, line 6 | 9 |
| 10 | Line 8 amount divided by line 9 amount | 10 |

| Section E - Distribution Allocations (see instructions) | (i) Excess Distributions | (ii) Underdistributions Pre-2021 | (iii) Distributable Amount for 2021 |
|---|---|--|---|
| 1 | Distributable amount for 2021 from Section C, line 6 | | |
| 2 | Underdistributions, if any, for years prior to 2021 (reasonable cause required - explain in Part VI). See instructions. | | |
| 3 | Excess distributions carryover, if any, to 2021 | | |
| a | From 2016 | | |
| b | From 2017 | | |
| c | From 2018 | | |
| d | From 2019 | | |
| e | From 2020 | | |
| f | Total of lines 3a through 3e | | |
| g | Applied to underdistributions of prior years | | |
| h | Applied to 2021 distributable amount | | |
| i | Carryover from 2016 not applied (see instructions) | | |
| j | Remainder. Subtract lines 3g, 3h, and 3i from line 3f. | | |
| 4 | Distributions for 2021 from Section D, line 7: \$ | | |
| a | Applied to underdistributions of prior years | | |
| b | Applied to 2021 distributable amount | | |
| c | Remainder. Subtract lines 4a and 4b from line 4. | | |
| 5 | Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions. | | |
| 6 | Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions. | | |
| 7 | Excess distributions carryover to 2022. Add lines 3j and 4c. | | |
| 8 | Breakdown of line 7: | | |
| a | Excess from 2017 | | |
| b | Excess from 2018 | | |
| c | Excess from 2019 | | |
| d | Excess from 2020 | | |
| e | Excess from 2021 | | |

SCHEDULE C
(Form 990)

Political Campaign and Lobbying Activities

OMB No. 1545-0047

2021

Department of the Treasury
Internal Revenue Service

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.**
 ▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

Open to Public Inspection

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

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

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

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

If the organization answered "Yes," on Form 990, Part IV, line 5 (Proxy Tax) (See separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (See separate instructions), then

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

| | |
|--|--|
| Name of organization NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. | Employer identification number 13-3223946 |
|--|--|

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

1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.

- 2 Political campaign activity expenditures ▶ \$ _____
- 3 Volunteer hours for political campaign activities _____

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

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

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

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

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

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule C (Form 990) 2021

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

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

| Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.) | | (a) Filing organization's totals | (b) Affiliated group totals | | | | | | | | | | | | |
|---|---|---|--|--------------------|-------------------------------|---|--|---|--|--|---|-------------------|--------------|--|--|
| 1a | Total lobbying expenditures to influence public opinion (grassroots lobbying) | 44,421. | | | | | | | | | | | | | |
| b | Total lobbying expenditures to influence a legislative body (direct lobbying) | 128,257. | | | | | | | | | | | | | |
| c | Total lobbying expenditures (add lines 1a and 1b) | 172,678. | | | | | | | | | | | | | |
| d | Other exempt purpose expenditures | 57,547,839. | | | | | | | | | | | | | |
| e | Total exempt purpose expenditures (add lines 1c and 1d) | 57,720,517. | | | | | | | | | | | | | |
| f | Lobbying nontaxable amount. Enter the amount from the following table in both columns. | 1,000,000. | | | | | | | | | | | | | |
| <table border="1"> <thead> <tr> <th>If the amount on line 1e, column (a) or (b) is:</th> <th>The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table> | | If the amount on line 1e, column (a) or (b) is: | The lobbying nontaxable amount is: | Not over \$500,000 | 20% of the amount on line 1e. | Over \$500,000 but not over \$1,000,000 | \$100,000 plus 15% of the excess over \$500,000. | Over \$1,000,000 but not over \$1,500,000 | \$175,000 plus 10% of the excess over \$1,000,000. | Over \$1,500,000 but not over \$17,000,000 | \$225,000 plus 5% of the excess over \$1,500,000. | Over \$17,000,000 | \$1,000,000. | | |
| If the amount on line 1e, column (a) or (b) is: | The lobbying nontaxable amount is: | | | | | | | | | | | | | | |
| Not over \$500,000 | 20% of the amount on line 1e. | | | | | | | | | | | | | | |
| Over \$500,000 but not over \$1,000,000 | \$100,000 plus 15% of the excess over \$500,000. | | | | | | | | | | | | | | |
| Over \$1,000,000 but not over \$1,500,000 | \$175,000 plus 10% of the excess over \$1,000,000. | | | | | | | | | | | | | | |
| Over \$1,500,000 but not over \$17,000,000 | \$225,000 plus 5% of the excess over \$1,500,000. | | | | | | | | | | | | | | |
| Over \$17,000,000 | \$1,000,000. | | | | | | | | | | | | | | |
| g | Grassroots nontaxable amount (enter 25% of line 1f) | 250,000. | | | | | | | | | | | | | |
| h | Subtract line 1g from line 1a. If zero or less, enter -0- | 0. | | | | | | | | | | | | | |
| i | Subtract line 1f from line 1c. If zero or less, enter -0- | 0. | | | | | | | | | | | | | |
| j | If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? | | <input type="checkbox"/> Yes <input type="checkbox"/> No | | | | | | | | | | | | |

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

| Lobbying Expenditures During 4-Year Averaging Period | | | | | |
|---|----------|------------|------------|------------|------------|
| Calendar year (or fiscal year beginning in) | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) Total |
| 2a Lobbying nontaxable amount | | 1,000,000. | 1,000,000. | 1,000,000. | 3,000,000. |
| b Lobbying ceiling amount (150% of line 2a, column(e)) | | | | | 4,500,000. |
| c Total lobbying expenditures | | 337,761. | 373,751. | 172,678. | 884,190. |
| d Grassroots nontaxable amount | | 250,000. | 250,000. | 250,000. | 750,000. |
| e Grassroots ceiling amount (150% of line 2d, column (e)) | | | | | 1,125,000. |
| f Grassroots lobbying expenditures | | 12,666. | 120,306. | 44,421. | 177,393. |

Schedule C (Form 990) 2021

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

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

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

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

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

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

Part IV Supplemental Information

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

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

Complete if the organization answered "Yes" on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2021

Open to Public Inspection

Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Employer identification number 13-3223946

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and two yes/no questions about donor property and grant fund usage.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include purpose of easements, number of easements, acreage, and expenses, and two yes/no questions about monitoring and requirements.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include reporting requirements for art and historical treasures, and amounts for revenue and assets.

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

Schedule D (Form 990) 2021

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

- 3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply):
- a Public exhibition
 - b Scholarly research
 - c Preservation for future generations
 - d Loan or exchange program
 - e Other _____
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

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

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
- b If "Yes," explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|---------------------------------|--------|
| c Beginning balance | 1c |
| d Additions during the year | 1d |
| e Distributions during the year | 1e |
| f Ending balance | 1f |
- 2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? Yes No
- b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII

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

| | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
|--|------------------|----------------|--------------------|----------------------|---------------------|
| 1a Beginning of year balance | 200,000. | | | | |
| b Contributions | | 200,000. | | | |
| c Net investment earnings, gains, and losses | | | | | |
| d Grants or scholarships | | | | | |
| e Other expenditures for facilities and programs | | | | | |
| f Administrative expenses | | | | | |
| g End of year balance | 200,000. | 200,000. | | | |

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment _____ %
 - b Permanent endowment 100.0000 %
 - c Term endowment _____ %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|--|--------------------------|-------------------------------------|
| (i) Unrelated organizations | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| (ii) Related organizations | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? | <input type="checkbox"/> | <input type="checkbox"/> |
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

| Description of property | (a) Cost or other basis (investment) | (b) Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|--|--------------------------------------|---------------------------------|------------------------------|----------------|
| 1a Land | | 505,203. | | 505,203. |
| b Buildings | | 857,182. | 689,517. | 167,665. |
| c Leasehold improvements | | | | |
| d Equipment | | 31,731. | 26,735. | 4,996. |
| e Other | | 3,571,346. | 3,000,397. | 570,949. |
| Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.) | | | | 1,248,813. |

Part VII Investments - Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

| (a) Description of security or category (including name of security) | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1) Financial derivatives | | |
| (2) Closely held equity interests | | |
| (3) Other | | |
| (A) | | |
| (B) | | |
| (C) | | |
| (D) | | |
| (E) | | |
| (F) | | |
| (G) | | |
| (H) | | |
| Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ▶ | | |

Part VIII Investments - Program Related.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

| (a) Description of investment | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1) | | |
| (2) | | |
| (3) | | |
| (4) | | |
| (5) | | |
| (6) | | |
| (7) | | |
| (8) | | |
| (9) | | |
| Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ▶ | | |

Part IX Other Assets.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

| (a) Description | (b) Book value |
|---|----------------|
| (1) | |
| (2) | |
| (3) | |
| (4) | |
| (5) | |
| (6) | |
| (7) | |
| (8) | |
| (9) | |
| Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶ | |

Part X Other Liabilities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

| 1. (a) Description of liability | (b) Book value |
|---|----------------|
| (1) Federal income taxes | |
| (2) DEFERRED COMPENSATION | 147,299. |
| (3) | |
| (4) | |
| (5) | |
| (6) | |
| (7) | |
| (8) | |
| (9) | |
| Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶ | 147,299. |

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII...

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

| | | | |
|----------|--|-----------|-------------|
| 1 | Total revenue, gains, and other support per audited financial statements | 1 | 43,105,547. |
| 2 | Amounts included on line 1 but not on Form 990, Part VIII, line 12: | | |
| a | Net unrealized gains (losses) on investments | 2a | -93,610. |
| b | Donated services and use of facilities | 2b | 72,500. |
| c | Recoveries of prior year grants | 2c | |
| d | Other (Describe in Part XIII.) | 2d | |
| e | Add lines 2a through 2d | 2e | -21,110. |
| 3 | Subtract line 2e from line 1 | 3 | 43,126,657. |
| 4 | Amounts included on Form 990, Part VIII, line 12, but not on line 1: | | |
| a | Investment expenses not included on Form 990, Part VIII, line 7b | 4a | 61,515. |
| b | Other (Describe in Part XIII.) | 4b | |
| c | Add lines 4a and 4b | 4c | 61,515. |
| 5 | Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.) | 5 | 43,188,172. |

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

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

| | | | |
|----------|---|-----------|-------------|
| 1 | Total expenses and losses per audited financial statements | 1 | 57,731,502. |
| 2 | Amounts included on line 1 but not on Form 990, Part IX, line 25: | | |
| a | Donated services and use of facilities | 2a | 72,500. |
| b | Prior year adjustments | 2b | |
| c | Other losses | 2c | |
| d | Other (Describe in Part XIII.) | 2d | |
| e | Add lines 2a through 2d | 2e | 72,500. |
| 3 | Subtract line 2e from line 1 | 3 | 57,659,002. |
| 4 | Amounts included on Form 990, Part IX, line 25, but not on line 1: | | |
| a | Investment expenses not included on Form 990, Part VIII, line 7b | 4a | 61,515. |
| b | Other (Describe in Part XIII.) | 4b | |
| c | Add lines 4a and 4b | 4c | 61,515. |
| 5 | Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.) | 5 | 57,720,517. |

Part XIII Supplemental Information.

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

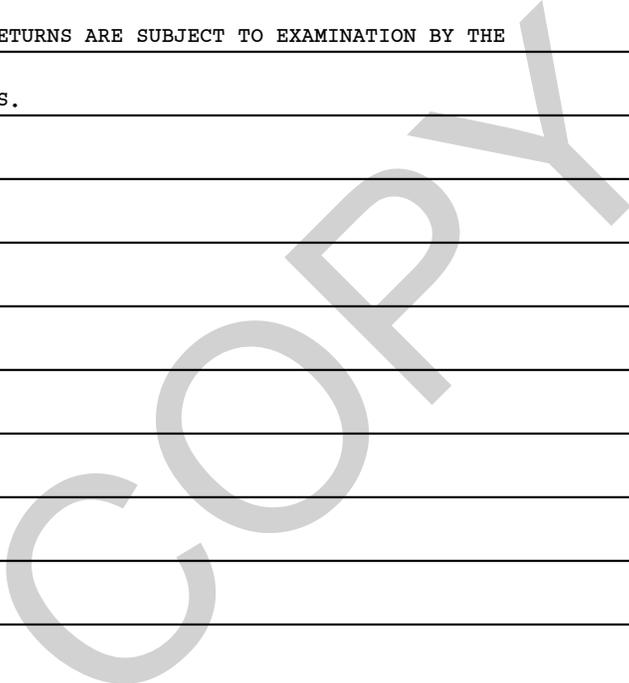
PART V, LINE 4:

NORD DEVELOPED A FORMAL ENDOWMENT SPENDING POLICY WHERE AS THE CORPUS SHALL NOT BE USED TO PAY CURRENT EXPENSES, OTHER THAN INVESTMENT SERVICE FEES. THE CORPUS SHALL BE INVESTED AND RETURNS MAY BE USED BY NORD ON AN ANNUAL BASIS, STARTING THREE YEARS AFTER THE FUNDS ARE INVESTED. THE ANNUAL SPENDING WILL BE CALCULATED AS THE GREATER OF ZERO OR HALF OF THE AVERAGE ANNUAL RETURN OVER THE PRIOR THREE YEARS, CALCULATED FROM THE CALENDAR YEAR-END BALANCE. NORD MAY DECIDE AT ITS DISCRETION TO DELAY OR FOREGO THE ANNUAL WITHDRAWAL FROM THE PORTFOLIO. NORD WILL NOT SPEND ENDOWED FUNDS FROM THE ENDOWMENT UNTIL AFTER MARCH 2024, THREE YEARS AFTER THE INITIAL INVESTMENT.

Part XIII Supplemental Information (continued)

PART X, LINE 2:

NORD ACCOUNTS FOR UNCERTAINTY IN INCOME TAXES IN ACCORDANCE WITH ASC
TOPIC, INCOME TAXES. THIS STANDARD CLARIFIES THE ACCOUNTING FOR
UNCERTAINTY IN TAX POSITIONS AND PRESCRIBES A RECOGNITION THRESHOLD AND
MEASUREMENT ATTRIBUTE FOR THE FINANCIAL STATEMENTS REGARDING A TAX
POSITION TAKEN OR EXPECTED TO BE TAKEN IN A TAX RETURN. NORD HAS
DETERMINED THAT THERE ARE NO UNCERTAIN TAX POSITIONS WHICH QUALIFY FOR
EITHER RECOGNITION OR DISCLOSURE IN THE FINANCIAL STATEMENTS AT DECEMBER
31, 2021. NORD'S INFORMATION RETURNS ARE SUBJECT TO EXAMINATION BY THE
FEDERAL AND STATE JURISDICTIONS.



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

| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|-------------------------------|--|--|-------------------------|--------------------------|------------------------------------|----------------------------------|---------------------------------------|---|
| | | SOUTH ASIA | SOFTWARE IN DEVELOPMENT | 71,900. | BANK OF AMERICA INTERNATIONAL WIRE | 0. | | BOOK |
| | | NORTH AMERICA | RESEARCH GRANT | 21,250. | BANK OF AMERICA INTERNATIONAL WIRE | 0. | | BOOK |
| | | EUROPE (INCLUDING ICELAND & GREENLAND) | RESEARCH GRANT | 49,998. | BANK OF AMERICA INTERNATIONAL WIRE | 0. | | BOOK |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |

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

3 Enter total number of other organizations or entities ▶ _____

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* Yes No

- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* Yes No

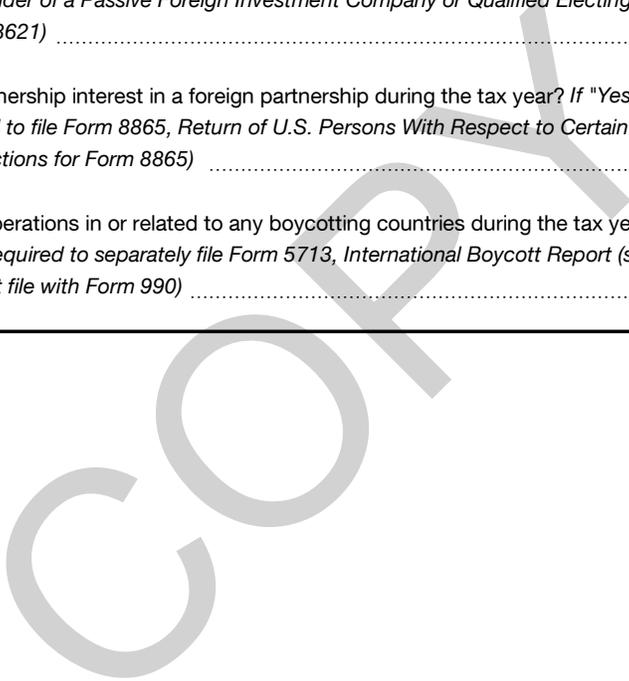
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471)* Yes No

- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* Yes No

- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* Yes No

- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)* Yes No

Schedule F (Form 990) 2021



Part V Supplemental Information

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

Multiple horizontal lines for supplemental information input.



**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990.
▶ Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2021

**Open to Public
Inspection**

Name of the organization **NATIONAL ORGANIZATION FOR RARE
DISORDERS, INC.**

Employer identification number
13-3223946

Part I General Information on Grants and Assistance

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- 2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1 (a) Name and address of organization or government | (b) EIN | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
|--|----------------|--|---------------------------------|---|--|--|---|
| ANN & ROBERT H. LURIE CHILDREN'S HOSPITAL OF CHICAGO - 225 E. CHICAGO AVE. - CHICAGO, IL 60611 | 36-2170833 | 501(C)(3) | 47,625. | 0. | | | RESEARCH GRANT |
| BOSTON CHILDRENS HOSPITAL PO BOX 414413 BOSTON, MA 02241 | 04-2774441 | 501(C)(3) | 24,800. | 0. | | | RESEARCH GRANT |
| BRIGHAM & WOMENS HOSPITAL - RESEARCH - 75 FRANCIS STREET - BOSTON, MA 02115 | 04-2312909 | 501(C)(3) | 25,000. | 0. | | | RESEARCH GRANT |
| CHILDREN'S HOSPITAL OF PHILADELPHIA - 2716 SOUTH STREET, 15361 - PHILADELPHIA, PA 19146 | 23-1352166 | 501(C)(3) | 25,000. | 0. | | | RESEARCH GRANT |
| HENRY M. JACKSON FOUNDATION FOR ADVANCEMENT OF MILITARY MEDICINE, INC. - 6720A ROCKLEDGE DRIVE, SUITE 100 - BETHESDA, MD 20817 | 52-1317896 | 501(C)(3) | 25,000. | 0. | | | RESEARCH GRANT |
| NYU SCHOOL OF MEDICINE ONE PARK AVE 6TH FLOOR NEW YORK, NY 10016 | 13-5562308 | 501(C)(3) | 24,963. | 0. | | | RESEARCH GRANT |

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ▶ 8.
- 3** Enter total number of other organizations listed in the line 1 table ▶ 5.

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

Schedule I (Form 990) 2021

Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--|------------|-------------------------------|--------------------------|----------------------------------|---|--|------------------------------------|
| OSLO UNIVERSITY HOSPITAL PEDER HEYERDAHL UTNE, HEAD OF RESEARCH ADMINISTRATION, RESEARCH SUPPORT UNIT | 98-1206495 | | 23,800. | 0. | | | RESEARCH GRANT |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA - 550 16TH ST - SAN FRANCISCO, CA 94143 | 94-6036493 | | 15,000. | 0. | | | RESEARCH GRANT |
| UNIVERSITY HEALTH NETWORK 190 ELIZABETH STREET TORORNTO, ONTARIO, CANADA M5G 2C4 | 11-9259505 | | 21,250. | 0. | | | RESEARCH GRANT |
| THE UNIVERSITY OF CHICAGO 6054 SOUTH DREXEL AVE SUITE 300 CHICAGO, IL 60619 | 36-2177139 | 501(C)(3) | 51,000. | 0. | | | RESEARCH GRANT |
| UNIVERSITY OF PITTSBURGH 116 ATWOOD STREET, SUITE 201 PITTSBURGH, PA 15260 | 25-0965591 | 501(C)(3) | 22,500. | 0. | | | RESEARCH GRANT |
| UNIVERSITY OF SOUTH CAROLINA 1600 HAMPTON STREET 6TH FLOOR COLUMBIA, SC 29208 | 57-6001153 | | 25,000. | 0. | | | RESEARCH GRANT |
| THE UNIVERSITY OF SHEFFIELD FIFTH COURT WESTERN BANK SHEFFIELD, UNITED KINGDOM S10 2TN | 98-0469910 | | 49,998. | 0. | | | RESEARCH GRANT |
| JOHNS HOPKINS UNIVERSITY 3910 KESWICK ROAD, N4327-B BALTIMORE, MD 21211 | 52-0595110 | | 40,000. | 0. | | | RESEARCH GRANT |
| | | | | | | | |

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of non-cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance |
|---------------------------------|--------------------------|--------------------------|-----------------------------------|---|---------------------------------------|
| PATIENT ASSISTANCE PROGRAMS | 9178 | 43,634,227. | 0. | BOOK | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

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

PART I, LINE 2:

ANY GRANTS AND SUPPORT GIVEN ARE CLOSELY MONITORED VIA REVIEW OF BACKUP

DOCUMENTATION AND PROOF OF EXPENSE.

**SCHEDULE J
(Form 990)**

Compensation Information

OMB No. 1545-0047

2021

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

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.

▶ Attach to Form 990.

▶ Go to www.irs.gov/Form990 for instructions and the latest information.

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization **NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.**

Employer identification number
13-3223946

Part I Questions Regarding Compensation

- 1a** Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.
- | | |
|--|--|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (such as maid, chauffeur, chef) |
- b** If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain
- 2** Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?
- 3** Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.
- | | |
|--|---|
| <input type="checkbox"/> Compensation committee | <input checked="" type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input checked="" type="checkbox"/> Compensation survey or study |
| <input type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |
- 4** During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:
- a** Receive a severance payment or change-of-control payment?
- b** Participate in or receive payment from a supplemental nonqualified retirement plan?
- c** Participate in or receive payment from an equity-based compensation arrangement?
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.
- Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.**
- 5** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:
- a** The organization?
- b** Any related organization?
- If "Yes" on line 5a or 5b, describe in Part III.
- 6** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:
- a** The organization?
- b** Any related organization?
- If "Yes" on line 6a or 6b, describe in Part III.
- 7** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III
- 8** Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III
- 9** If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

| | Yes | No |
|-----------|-----|----|
| 1b | | |
| 2 | | |
| 4a | | X |
| 4b | | X |
| 4c | | X |
| 5a | | X |
| 5b | | X |
| 6a | | X |
| 6b | | X |
| 7 | | X |
| 8 | | X |
| 9 | | |

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

Schedule J (Form 990) 2021

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 on 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 aren't listed on Form 990, Part VII.

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

| (A) Name and Title | | (B) Breakdown of W-2 and/or 1099-MISC and/or 1099-NEC compensation | | | (C) Retirement and other deferred compensation | (D) Nontaxable benefits | (E) Total of columns (B)(i)-(D) | (F) Compensation in column (B) reported as deferred on prior Form 990 |
|---|------|--|-------------------------------------|-------------------------------------|--|-------------------------|---------------------------------|---|
| | | (i) Base compensation | (ii) Bonus & incentive compensation | (iii) Other reportable compensation | | | | |
| (1) PETER SALTONSTALL PRESIDENT/CEO | (i) | 452,672. | 0. | 0. | 26,000. | 10,275. | 488,947. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (2) PAMELA GAVIN CHIEF OPERATING OFFICER | (i) | 345,320. | 0. | 0. | 10,451. | 10,053. | 365,824. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (3) PRASHANT GOEL VP INFORMATION TECHNOLOGY | (i) | 258,821. | 0. | 0. | 12,976. | 1,832. | 273,629. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (4) ALEXA MOORE VP OF DEVELOPMENT | (i) | 218,063. | 0. | 0. | 15,994. | 29,067. | 263,124. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (5) RACHEL SHER VP POLICY & REGULATORY AFFAIRS | (i) | 225,960. | 0. | 0. | 19,500. | 1,112. | 246,572. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (6) EDWARD NEILAN CHIEF MEDICAL & SCIENTIFIC OFFICER | (i) | 180,810. | 0. | 0. | 14,323. | 15,260. | 210,393. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (7) VINCENT J. MURPHY, JR. VP FINANCE | (i) | 129,355. | 0. | 0. | 13,138. | 28,712. | 171,205. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (8) JILL POLLANDER VP PATIENT SERVICES | (i) | 139,242. | 0. | 0. | 19,500. | 10,223. | 168,965. | 0. |
| | (ii) | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| | (i) | | | | | | | |
| | (ii) | | | | | | | |
| | (i) | | | | | | | |
| | (ii) | | | | | | | |
| | (i) | | | | | | | |
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| | (ii) | | | | | | | |
| | (i) | | | | | | | |
| | (ii) | | | | | | | |

Part III Supplemental Information

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

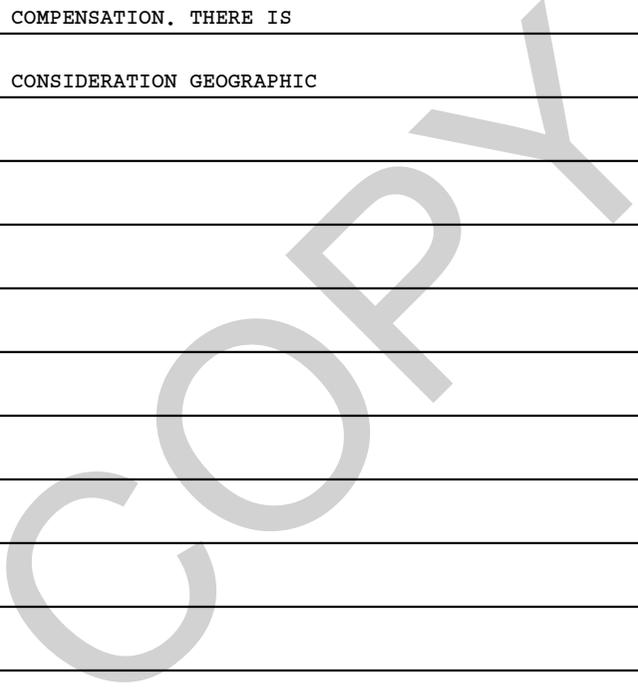
PART I, LINE 3:

THE BOARD OF DIRECTORS REVIEWS EXTERNAL SURVEYS, DOL, BLS, AND ACCOUNTEMP

SURVEYS FOR DECISIONS ON THE EXECUTIVE DIRECTOR'S COMPENSATION. THERE IS

ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC

SETTINGS, SKILLS, AND EDUCATION.



**SCHEDULE O
(Form 990)**

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2021

Open to Public
Inspection

| | | | |
|--------------------------|---|--------------------------------|------------|
| Name of the organization | NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. | Employer identification number | 13-3223946 |
|--------------------------|---|--------------------------------|------------|

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

EDUCATION, ADVOCACY AND RESEARCH.

FORM 990, PART III, LINE 2, NEW PROGRAM SERVICES:

NORD RARE DISEASE CENTERS OF EXCELLENCE PROGRAM - SEE PART III, LINE 4D

BELOW FOR A DETAILED DESCRIPTION.

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

NORD'S EDUCATIONAL INITIATIVES STRIVE TO EMPOWER PATIENTS AND THEIR

FAMILIES, INFORM STUDENTS OF ALL AGES, AND SUPPORT THE VITALLY

IMPORTANT WORK OF PHYSICIANS AND OTHER HEALTHCARE PROFESSIONALS IN

CREATING A BETTER UNDERSTANDING OF RARE DISEASES. THIS IS DONE THROUGH

THE DEVELOPMENT OF NORD'S RARE DISEASE DATABASE, EDUCATIONAL WEBINARS

AND VIDEOS, AND ROBUST EDUCATIONAL PROGRAMMING THROUGH NORD'S CME

PARTNERSHIPS AND AT NORD'S RARE DISEASES AND ORPHAN PRODUCTS

BREAKTHROUGH SUMMIT (RARE SUMMIT). IN 2021 OVER 900 PEOPLE VIRTUALLY

ATTENDED NORD'S RARE SUMMIT WHERE KEY STAKEHOLDER IN THE RARE DISEASE

SPACE GATHER TO LEARN, CONNECT, AND CREATE POSITIVE CHANGE FOR THE

BROADER RARE DISEASE COMMUNITY. ALSO, IN 2021 THERE WERE OVER 68

MILLION VISITORS TO THE ORGANIZATION'S WEBSITE TO READ NORD'S RARE

DISEASE REPORTS WHICH OFFER INFORMATION ABOUT EACH RARE DISEASE IN EASY

TO UNDERSTAND LANGUAGE.

EXPENSES \$ 1,153,107. INCLUDING GRANTS OF \$ 0. REVENUE \$ 2,046,735.

MEMBERSHIP: NORD WAS FOUNDED ON THE PRINCIPLES OF COLLABORATION AND A

UNITED VOICE, AND WE PROVIDE GUIDANCE AND SUPPORT AT ALL PHASES OF

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

Schedule O (Form 990) 2021

132211 11-11-21

| | |
|---|---|
| Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. | Employer identification number 13-3223946 |
|---|---|

DEVELOPMENT, AS ORGANIZATIONS EVOLVE. NORD OFFERS ITS MEMBERS EDUCATIONAL WEBINARS AND REGIONAL MEMBERSHIP MEETINGS PROVIDE OPPORTUNITIES TO INTERACT WITH OTHER LEADERSHIP OF OTHER PATIENT ORGANIZATIONS AND TO BUILD CAPACITY BY ADOPTING BEST PRACTICES. AS OF DECEMBER 31, 2021 THERE WERE 337 PATIENT ORGANIZATIONS THAT WERE MEMBERS.

EXPENSES \$ 729,935. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

THE NORD RARE DISEASE CENTERS OF EXCELLENCE PROGRAM WAS ESTABLISHED TO SELECT AND TO COLLABORATE WITH A NETWORK OF US MEDICAL INSTITUTIONS WITH EXCEPTIONAL CLINICAL AND RESEARCH PROGRAMS FOR PATIENTS WITH RARE DISEASES, WHO WILL WORK COLLABORATIVELY WITH NORD, WITH ONE ANOTHER, AND WITH THEIR LOCAL COMMUNITIES OF PHYSICIANS, CAREGIVERS, AND PATIENTS TO SHARE EXPERT KNOWLEDGE, DEFINE STANDARDS OF PRACTICE FOR RARE DISEASES, ACCELERATE DIAGNOSIS, AND IMPROVE PATIENT CARE, TREATMENT, AND RESEARCH IN RARE DISEASES. AS OF DECEMBER 2021, THERE WERE 31 DESIGNATED NORD RARE DISEASE CENTERS OF EXCELLENCE.

EXPENSES \$ 101,666. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION B, LINE 11B:

THE 990 IS REVIEWED BY THE VP OF FINANCE, CEO, FINANCE COMMITTEE, AND AUDIT COMMITTEE PRIOR TO FILING. THE 990 IS PROVIDED TO ALL MEMBERS OF THE BOARD OF DIRECTORS FOR REVIEW PRIOR TO BEING FILED.

FORM 990, PART VI, SECTION B, LINE 12C:

THE BOARD OF DIRECTORS ARE REQUIRED TO COMPLETE AN ANNUAL REVIEW OF THE ORGANIZATION'S CONFLICT OF INTEREST POLICY. THE MEMBERS OF THE BOARD ARE ANNUALLY REQUIRED TO REPORT IF THEY HAVE OR DO NOT HAVE ANY KNOWN CONFLICTS

| | |
|---|---|
| Name of the organization NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. | Employer identification number 13-3223946 |
|---|---|

OF INTEREST. THE EXECUTIVE COMMITTEE IS ALSO REQUIRED TO ANNUALLY SIGN OFF AS TO ANY KNOWN CONFLICTS THAT EXIST.

FORM 990, PART VI, SECTION B, LINE 15:

THE BOARD OF DIRECTORS REVIEWS EXTERNAL MARKET SURVEYS, DOL, BLS, AND ACCOUNTEMP SURVEYS FOR DECISIONS ON THE EXECUTIVE DIRECTOR COMPENSATION. THERE IS ALSO A SALARY ADMINISTRATION PLAN THAT TAKES INTO CONSIDERATION GEOGRAPHIC SETTINGS, SKILLS, AND EDUCATION.

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

CT, NY, AL, CA, FL, GA, IL, KS, KY, MA, MD, MI, MN, MS, NC, NH, NJ, NM, OK, OR, PA, RI, SC, TN, UT VA, WI, WV, AR, HI

FORM 990, PART VI, SECTION C, LINE 19:

GOVERNING DOCUMENTS ARE MADE AVAILABLE UPON REQUEST.

FORM 990, PART XII, LINE 2C:

THE BOARD OF DIRECTORS ASSUMES RESPONSIBILITY FOR OVERSIGHT OF THE AUDIT OF ITS FINANCIAL STATEMENTS AND SELECTION OF AN INDEPENDENT ACCOUNTANT.

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

Department of the Treasury
Internal Revenue Service

▶ **File a separate application for each return.**
▶ **Go to www.irs.gov/Form8868 for the latest information.**

Electronic filing (e-file). You can electronically file Form 8868 to request a 6-month automatic extension of time to file any of the forms listed below with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts, for which an extension request must be sent to the IRS in paper format (see instructions). For more details on the electronic filing of this form, visit www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits.

Automatic 6-Month Extension of Time. Only submit original (no copies needed).

All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

| | | |
|--|---|--|
| Type or print | Name of exempt organization or other filer, see instructions. NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. | Taxpayer identification number (TIN) 13-3223946 |
| File by the due date for filing your return. See instructions. | Number, street, and room or suite no. If a P.O. box, see instructions. 1900 CROWN COLONY DR., 3RD FL., 310 | |
| | City, town or post office, state, and ZIP code. For a foreign address, see instructions. QUINCY, MA 02169 | |

Enter the Return Code for the return that this application is for (file a separate application for each return) 0 1

| Application Is For | Return Code | Application Is For | Return Code |
|--|-------------|-----------------------------------|-------------|
| Form 990 or Form 990-EZ | 01 | Form 1041-A | 08 |
| Form 4720 (individual) | 03 | Form 4720 (other than individual) | 09 |
| Form 990-PF | 04 | Form 5227 | 10 |
| Form 990-T (sec. 401(a) or 408(a) trust) | 05 | Form 6069 | 11 |
| Form 990-T (trust other than above) | 06 | Form 8870 | 12 |
| Form 990-T (corporation) | 07 | | |

VINCENT MURPHY

• The books are in the care of ▶ 1900 CROWN COLONY DRIVE, 3RD FLOOR - QUINCY, MA 02169

Telephone No. ▶ 617-249-7300 Fax No. ▶ _____

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

1 I request an automatic 6-month extension of time until NOVEMBER 15, 2022, to file the exempt organization return for the organization named above. The extension is for the organization's return for:
▶ calendar year 2021 or
▶ tax year beginning _____, and ending _____.

2 If the tax year entered in line 1 is for less than 12 months, check reason: Initial return Final return
 Change in accounting period

| | | | |
|---|-----------|----|----|
| 3a If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions. | 3a | \$ | 0. |
| b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. | 3b | \$ | 0. |
| c Balance due. Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions. | 3c | \$ | 0. |

Caution: If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-TE and Form 8879-TE for payment instructions.