| | May the IRS discuss this return with the preparer shown above? See instructions | | | | |
|--|---|--|--|--|--|
| For Paperwork Reduction Act Notice, see the separate instructions. | | | | | |
| | EEA | | | | |

Paid

Preparer

Use Only

John Mullins

Firm's name

Firm's address

| st | ructi | ions. | | | |
|----|-------|-------|--|--|--|
| | | | | | |

John Mullins

7625 Wisconsin Avenue

Bethesda MD 20814

Mullins, PC

11-13-2023

X Yes No Form 990 (2022)

202-770-6371

P01429307

self-employed

Firm's EIN

Phone no.

| Do not enter social security numbers on this form as it may be made public. | |
|---|--|

Return of Organization Exempt From Income Tax

| Department of the Treasury Do not enter social security numbers on this form as it may be made public. | | | | | Open to Public | | | | | | |
|---|-------------|--------------------|--|--|----------------------|-------------------|------------|------------------|---------------|----------------------------|--|
| | | ue Service | Go to wi | ww.irs.gov/Form990 for i | nstructions an | d the latest | informa | tion. | | Inspection | |
| A F | or the | e 2022 calend | lar year, or tax year begir | ning | 07-0 | 1,2022, | and end | ing | 06 | -30,2023 | |
| B c | heck if a | applicable: | C Name of organization Sm | ith-Kingsmore Sy | ndrome Fou | ndation | | | D Emplo | over identification number | |
| A | ddress | change | Doing business as | | | | - | | | 84-2913037 | |
| _ | lame ch | ange | Number and street (or P.O. bo | x if mail is not delivered to street a | address) | | Room/su | ite | E Teleph | one number | |
| Ir | nitial retu | ırn | 5903 Franklin | Trl | | | | | | (513) 755-1705 | |
| F | inal retu | rn/terminated | City or town, state or province | , country, and ZIP or foreign posta | al code | | | | G Gross | receipts | |
| A | mended | l return | Liberty Twp, C | DH 45011 | | | | | \$ | 74,750 | |
| Α | pplicatio | on pending | F Name and address of principa | l officer: Sarah Lepc | ore | | | H(a) Is this a g | roup return f | or subordinates? Yes X No | |
| | | | Same as C abov | re | | | | H(b) Are all s | subordinate | s included? Yes No | |
| I T | ax-exem | npt status: 🛛 🗴 | 501(c)(3) 501(c) (|) (insert no.) 4947 | '(a)(1) or 5 | 27 | | lf "No," | attach a lis | t. See instructions | |
| JV | Vebsite: | | ps://smithkingsmo | ore.org | | | | H(c) Group e | exemption r | number | |
| | | | | ociation Other | L | Year of formation | tion: 201 | 9 м s | State of lega | al domicile: OH | |
| Pa | rt I | Summar | У | | | | | | | | |
| | 1 | Briefly descr | ibe the organization's miss | ion or most significant acti | ivities: <u>Fund</u> | researd | ch to 1 | better 1 | unders | stand | |
| e | | <u>Smith-Ki</u> | ngsmore syndrome | and find treatmen | nts to imp | rove pat | ient o | quality | of li | fe and, | |
| anc | | ultimate | ly, a cure. With | a 3-year, \$600K (| CZI Rare A | s One Pr | oject | grant, | stren | gthen our | |
| & Governance | | organiza | tional capacity a | nd align patients | s and resea | archers. | | | | | |
| ð | 2 | Check this b | ox 🔲 if the organization o | liscontinued its operations | or disposed of | more than 2 | 25% of its | net assets. | | | |
| ອ ອ | 3 | Number of v | oting members of the gove | rning body (Part VI, line 1 | a) | | | | 3 | 8 | |
| ŝ | 4 | Number of in | ndependent voting member | rs of the governing body (F | Part VI, line 1b) | | | | 4 | 8 | |
| viti | 5 | Total numbe | r of individuals employed ir | n calendar year 2022 (Parl | t V, line 2a) 🛛 🔒 | | | | 5 | 1 | |
| Activities | 6 | Total numbe | r of volunteers (estimate if | necessary) | | | | | 6 | 10 | |
| ◄ | 7a | Total unrelate | ed business revenue from | Part VIII, column (C), line | 12 | | | | 7a | 0 | |
| | b | Net unrelate | d business taxable income | from Form 990-T, Part I, I | ine 11 • • • • | | | | 7b | 0 | |
| | | | | | | | | Prior Year | | Current Year | |
| | 8 | Contribution | s and grants (Part VIII, line | 1h) | | | | 655 | ,233 | 74,563 | |
| anı | 9 | Program ser | vice revenue (Part VIII, line | e 2g) •••••• | | | | | | 0 | |
| Revenue | 10 | Investment i | ncome (Part VIII, column (/ | A), lines 3, 4, and 7d) •• | | | | | | 0 | |
| Re | 11 | Other revenue | ue (Part VIII, column (A), lir | nes 5, 6d, 8c, 9c, 10c, and | 11e) | | | | 481 | 187 | |
| | 12 | Total revenue | e - add lines 8 through 11 (| must equal Part VIII, colu | mn (A), line 12) | 2) • • • • • 655 | | | ,714 | 74,750 | |
| | 13 | Grants and s | similar amounts paid (Part | IX, column (A), lines 1-3) | | | | 58,853 | | 93,764 | |
| | 14 | Benefits paid | d to or for members (Part I) | K, column (A), line 4) | | | | | | | |
| s | 15 | Salaries, oth | s, other compensation, employee benefits (Part IX, column (A), lines 5-10) • • • • • | | | 89,688 | | | | | |
| ISe | 16a | Professional | fundraising fees (Part IX, | column (A), line 11e) ••• | | | | | 600 | 0 | |
| Expenses | | | sing expenses (Part IX, co | (): | | 60,406 | _ | | | | |
| ш | 17 | Other expen | ses (Part IX, column (A), li | nes 11a-11d, 11f-24e) | | | | 24 | ,740 | 41,254 | |
| | 18 | • | ses. Add lines 13-17 (must | | . , | | | 84 | ,193 | 224,706 | |
| | 19 | Revenue les | s expenses. Subtract line | 18 from line 12 | | | | 571 | ,521 | (149,956) | |
| or | | | | | | | Begi | nning of Curre | ent Year | End of Year | |
| sets | 20 | | (Part X, line 16) | | | | | 596 | ,122 | 509,150 | |
| Sofe 20 Total assets (Part X, line 16) B 21 Total liabilities (Part X, line 26) Control 1 22 Net assets or fund balances. Subtract line 21 from line 20 Control 1 | | | | | | | | | 62,984 | | |
| | | | r fund balances. Subtract | line 21 from line 20 • • • | | | | 596 | ,122 | 446,166 | |
| | rt II | _ | re Block | | | | | | | | |
| | | | clare that I have examined this retu claration of preparer (other than of | | | | | owledge and be | elief, it is | | |
| , | ., | | | , | | , | | | | | |
| Sig | n | | h Lepore | | | | | | _ L | - | |
| - | | Signature of offic | cer | | | | | | Date | e | |
| Her | e | | h Lepore, Preside | nt | | | | | | | |
| | | Type or print nar | | Deserves and a sing of | | Data | | | | DTIN | |
| | | Print/Type pre | eparer's name | Preparer's signature | | Date | | Check | l if | PTIN | |

| | 9 | Δ | 9 | 5 |
|--|---|---|---|---|
| | 2 | U | Z | _ |

OMB No. 1545-0047

Form **990**

| - | 990 (2022) Smith-Kingsmore Syndrome Foundation 84-2913037 Page 2 |
|-----|---|
| Pa | rt III Statement of Program Service Accomplishments |
| | Check if Schedule O contains a response or note to any line in this Part III |
| 1 | Briefly describe the organization's mission: |
| | Fund research to better understand Smith-Kingsmore syndrome and find treatments to improve |
| | patient quality of life and, ultimately, a cure. With a 3-year, \$600K CZI Rare As One Project |
| | grant, strengthen our organizational capacity and align patients and researchers. |
| 2 | Did the organization undertake any significant program services during the year which were not listed on the |
| | prior Form 990 or 990-EZ? |
| | 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? |
| | 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 \$138,352 including grants of \$93,764) (Revenue \$) |
| | This year, Smith-Kingsmore Syndrome Foundation funded two research projects - at the University of Florida in the lab of Dr Andrew Liu, and the University of California-Davis in the lab of Dr |
| | Joanna Chiu - for a total investment of \$93,764. The research investments target both basic |
| | understanding of the syndrome (with a long-term view to a cure) as well as cutting-edge research |
| | and screening of FDA-approved drugs for nearer-term application in managing and treating the mos |
| | pressing medical issues caused by Smith-Kingsmore syndrome. In addition, the Foundation expanded |
| | the reach of scientific/health information about Smith-Kingsmore syndrome by translating the |
| | patient/provider guide into 12 languages, hosting community meetings in English, Spanish and |
| | Portuguese, collaborating with other patient organizations on a quality-of-life/research survey, |
| | and presenting research findings at a national research/clinician conference. |
| | |
| | |
| 4b | (Code:) (Expenses \$ including grants of \$) (Revenue \$) |
| | |
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| | |
| | |
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| | |
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| | |
| | |
| 4c | (Code:) (Expenses \$ including grants of \$) (Revenue \$) |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| 4d | Other program services (Describe on Schedule O.) |
| | (Expenses \$ including grants of \$) (Revenue \$) |
| 4e | Total program service expenses 138,352 |
| EEA | Form 990 (2022) |

| Form 990 (2 | 2022 |
|-------------|------|
| Part IV | |

| 2) | Smith-Kingsmore | Syndrome | Foundation |
|--------------|-----------------|----------|------------|
| Checklist of | Required Schedu | les | |

| | | | Yes | No |
|------|--|----------|-----|----|
| 1 | Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," | | | |
| - | | 1 | x | |
| 2 | Is the organization required to complete Schedule B, Schedule of Contributors? See instructions | 2 | x | |
| 3 | Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to | | | |
| • | candidates for public office? If "Yes," complete Schedule C, Part I | 3 | | х |
| 4 | Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) | – | | |
| - | election in effect during the tax year? If "Yes," complete Schedule C, Part II | 4 | | x |
| 5 | Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, | | | |
| Ŭ | assessments, or similar amounts as defined in Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III | 5 | | x |
| 6 | Did the organization maintain any donor advised funds or any similar funds or accounts for which donors | L. | | |
| Ŭ | have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If | | | |
| | "Yes," complete Schedule D, Part I | 6 | | 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? If "Yes," complete Schedule D, Part II | 7 | | x |
| 8 | Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes,"</i> | <u> </u> | | |
| • | complete Schedule D, Part III | 8 | | 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? If "Yes," complete Schedule D, Part IV | 9 | | x |
| 10 | Did the organization, directly or through a related organization, hold assets in donor-restricted endowments | – | | |
| | or in quasi endowments? If "Yes," complete Schedule D, Part V | 10 | | 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. | | | |
| а | Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes,"</i> | | | |
| | complete Schedule D, Part VI | 11a | | х |
| b | Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more | | | |
| | of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII | 11b | | х |
| с | Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more | | | |
| | of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII | 11c | | х |
| d | Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets | | | |
| | reported in Part X, line 16? If "Yes," complete Schedule D, Part IX | 11d | | х |
| е | Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X | 11e | | 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)? If "Yes," complete Schedule D, Part X | 11f | | х |
| 12a | Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete | | | |
| | Schedule D. Parts XI and XII | 12a | | х |
| b | Was the organization included in consolidated, independent audited financial statements for the tax year? If | | | |
| | "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional | 12b | | х |
| 13 | Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E | 13 | | х |
| 14a | Did the organization maintain an office, employees, or agents outside of the United States? | 14a | | х |
| b | Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, | | | |
| | fundraising, business, investment, and program service activities outside the United States, or aggregate | | | |
| | foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV | 14b | | х |
| 15 | Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or | | | |
| | for any foreign organization? If "Yes," complete Schedule F, Parts II and IV | 15 | | х |
| 16 | Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other | | | |
| | assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV | 16 | | х |
| 17 | Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on | | | |
| | Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I See instructions | 17 | | 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? If "Yes," complete Schedule G, Part II | 18 | | x |
| 19 | Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? | | | |
| | If "Yes," complete Schedule G, Part III | 19 | | x |
| 20 a | Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H | 20a | | х |
| b | If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? | 20b | | |
| 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? If "Yes," complete Schedule I, Parts I and II | 21 | х | |

| | n 990 (2022) Smith-Kingsmore Syndrome Foundation | 84-29130 | 37 | Р | age 4 |
|-----|---|----------|----------|-----|--------------|
| Pa | rt 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? If "Yes," complete Schedule I, Parts I and III | | 22 | | х |
| 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? If "Yes," complete Schedule J | | 23 | | х |
| 24a | Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than | | | | |
| | \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b | | | | |
| | through 24d and complete Schedule K. If "No," go to line 25a | | 24a | | x |
| b | Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? | | 24b | | ┝─── |
| С | Did the organization maintain an escrow account other than a refunding escrow at any time during the year | | | | |
| | to defease any tax-exempt bonds? | | 24c | | |
| d | Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? | | 24d | | ┝─── |
| 25a | Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit | | | | |
| | transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I | | 25a | | 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? | | | | |
| | If "Yes," complete Schedule L, Part I | | 25b | | 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 or any of these persons? If "Yes," complete Schedule L, Part II | | 26 | | 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? If "Yes," complete Schedule L, Part III | | 27 | | 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): | | | | |
| а | A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If | | | | |
| | "Yes," complete Schedule L, Part IV | | 28a | | X |
| b | A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV | | 28b | | x |
| С | A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If | | | | |
| ~~ | "Yes," complete Schedule L, Part IV | | 28c | | X |
| 29 | Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> | | 29 | | x |
| 30 | Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified | | | | |
| | conservation contributions? If "Yes," complete Schedule M | | 30 31 | | X |
| 31 | Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> | | 31 | | x |
| 32 | Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," | | 22 | | |
| 33 | complete Schedule N, Part II | | 32 | | x |
| 33 | sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I | | 33 | | |
| 34 | Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, | | - 33 | | <u>x</u> |
| J-+ | or IV, and Part V, line 1 | | 34 | | v |
| 35a | Did the organization have a controlled entity within the meaning of section 512(b)(13)? | | 35a | | x x |
| b | If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a | | 554 | | <u> </u> |
| | controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2 | | 35b | | |
| 36 | Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable | | | | |
| | related organization? If "Yes," complete Schedule R, Part V, line 2 · · · · · · · · · · · · · · · · · · | | 36 | | 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? If "Yes," complete Schedule R, Part VI | | 37 | | x |
| 38 | Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and | | | | |
| | 19? Note: All Form 990 filers are required to complete Schedule O | | 38 | х | l |
| Par | | | | | |
| | Check if Schedule O contains a response or note to any line in this Part V | | | | Π |
| | | | | Yes | No |
| 1a | Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable | 1 | | | |
| b | Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable | 0 | | | |
| c | Did the organization comply with backup withholding rules for reportable payments to vendors and | | | | |
| | reportable gaming (gambling) winnings to prize winners? | | 1c | x | |
| | | | _ | _ | |

| Form | 990 (2022) Smith-Kingsmore Syndrome Foundation 84-29130 | 37 | F | Page 5 |
|--------|--|----------|-----|----------|
| Par | t 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 1 | | | |
| b | If at least one is reported on line 2a, did the organization file all required federal employment tax returns? | 2b | x | |
| 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 | | v |
| | Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? | 5a 5b | | X |
| b | If "Yes" to line 5a or 5b, did the organization file Form 8886-T? | | | X |
| C C | | 5c | | <u> </u> |
| 6a | Does the organization have annual gross receipts that are normally greater than \$100,000, and did the | 0.0 | | |
| | 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). | | | |
| а | 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 | | |
| С | 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 | | | |
| е | Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? | 7e | | х |
| 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. | | | |
| а | 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: | | | |
| а | Initiation fees and capital contributions included on Part VIII, line 12 | | | |
| b | Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities | | | |
| 11 | Section 501(c)(12) organizations. Enter: | 1 | | |
| а | Gross income from members or shareholders | | | |
| b | Gross income from other sources (Do not net amounts due or paid to other sources | 1 | | |
| -' | against amounts due or received from them.). | | | |
| 12a | Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? | 12a | | |
| b | If "Yes," enter the amount of tax-exempt interest received or accrued during the year | - | | |
| 13 | Section 501(c)(29) qualified nonprofit health insurance issuers. | 1 | | |
| а | Is the organization licensed to issue qualified health plans in more than one state? | 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 | | | |
| с | Enter the amount of reserves on hand | 1 | | |
| 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 | | <u> </u> |
| 15 | Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or | | | <u> </u> |
| | 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, or any any disqualified or other person 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. | | | |

| _ | m 990 (2022) Smith-Kingsmore Syndrome Foundation 84-29130 | | P | age 6 |
|------------|--|------|-----|-------|
| Pa | art 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 in Schedule O. See instructions. | | | _ |
| | Check if Schedule O contains a response or note to any line in this Part VI | | | х |
| Se | ction A. Governing Body and Management | | | |
| | | | Yes | No |
| 1a | Enter the number of voting members of the governing body at the end of the tax year | | | |
| | 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. | | | |
| b | Enter the number of voting members included in line 1a, above, who are independent 1b 8 | | | |
| 2 | Did any officer, director, trustee, or key employee have a family relationship or a business relationship with | | | |
| | any other officer, director, trustee, or key employee? | 2 | х | |
| 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? | 3 | | х |
| 4 | Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? | 4 | | х |
| 5 | Did the organization become aware during the year of a significant diversion of the organization's assets? | 5 | | х |
| 6 | Did the organization have members or stockholders? | 6 | | х |
| 7a | Did the organization have members, stockholders, or other persons who had the power to elect or appoint | | | |
| | one or more members of the governing body? | 7a | | х |
| b | Are any governance decisions of the organization reserved to (or subject to approval by) members, | | | |
| | stockholders, or persons other than the governing body? | 7b | | х |
| 8 | Did the organization contemporaneously document the meetings held or written actions undertaken during | | | |
| | the year by the following: | | | |
| а | The governing body? | 8a | х | |
| b | Each committee with authority to act on behalf of the governing body? | 8b | х | |
| 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 | 9 | | х |
| <u>Sec</u> | tion B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.) | | | |
| | | | Yes | No |
| 10a | Did the organization have local chapters, branches, or affiliates? | 10a | | х |
| b | If "Yes," did the organization have written policies and procedures governing the activities of such chapters, | | | |
| | affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? | 10b | | |
| 11a | Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? | 11a | х | |
| b | 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 | 12a | х | |
| b | Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? . | 12b | х | |
| С | Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," | | | |
| | describe on Schedule O how this was done | 12c | х | |
| 13 | Did the organization have a written whistleblower policy? | 13 | | х |
| 14 | Did the organization have a written document retention and destruction policy? | 14 | | х |
| 15 | Did the process for determining compensation of the following persons include a review and approval by | | | |
| | independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? | | | |
| а | The organization's CEO, Executive Director, or top management official • • • • • • • • • • • • • • • • • • • | 15a | | х |
| b | Other officers or key employees of the organization | 15b | | х |
| • • | 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? | 16a | | х |
| b | If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its | | | |
| | participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the | | | |
| 800 | organization's exempt status with respect to such arrangements? | 16b | | |
| | tion C. Disclosure | | | |
| 17 | List the states with which a copy of this Form 990 is required to be filed Statement #17 Continue Control of the Former 4000 (4004 or 4004 A if arriver light) 000 and 000 T (continue Control of the Former 4000 C (continue Control of the Former 4000 C (continue C (cont | | | |
| 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. | | | |
| 4.0 | Own website Another's website X 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. | | | |
| | The Organization (513)755-1705, 5903 Franklin Trl, Liberty Twp, OH 45011 | | | |

| Form 990 (202 | 2) Smith-Kingsmore Syndrome Foundation | 84-2913037 | Page 7 | | | | | |
|------------------|--|--------------------|---------|--|--|--|--|--|
| Part VII | Compensation of Officers, Directors, Trustees, Key Employees, Highest C | ompensated Employe | es, 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 E | mployees | | | | | | |
| 1a Complete th | a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the | | | | | | | |
| organization's t | ax 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, box 6 of 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 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.

| | | | inpe | 1150 | ieu a | any cu | nen | | liusiee. | |
|---------------------------------|----------------------|-----------------------------------|---|---------|--------------|---------------------------------|--------|----------------------------------|-----------------------------------|------------------------------|
| | | | | (| (C) | | | | | |
| (A) | (B) | | Position (do not check more than one | | | | (D) | (E) | (F) | |
| Name and title | Average | • | | | | han one s both a | | Reportable | Reportable | Estimated amount |
| | hours | | | | | r/trustee | | compensation | compensation | of other |
| | per week | | | | - | _ | | from the | from related | compensation |
| | (list any | 우 코 | Ľ. | Ó | ۲. | er Hi | Fo | organization (W-2/ 1099-MISC/ | organizations (W-2/ 1099-MISC/ | from the organization and |
| | hours for related | divid | stitu | Officer | y ei | ghe: | Former | 1099-NEC) | 1099-NEC) | related organizations |
| | organizations | ctor | tiona | | Key employee | st co yee | Ä | | | |
| | below | Individual trustee or director | Institutional trustee | | yee | mpe | | | | |
| | dotted line) | ee | stee | | | Highest compensated employee | | | | |
| | | | | | | ted | | | | |
| | | | | | | | | | | |
| (1) Susan Dando | 40.00 | | | | | | | | | |
| Executive Director | | | | х | | | | 81,865 | 0 | 0 |
| (2) Matt Walsh | 1.00 | | | | | | | | | |
| Director | | х | | | | | | 0 | 0 | 0 |
| (3) Eric Kelly | 5.00 | | | | | | | | | |
| Director | | х | | | | | | 0 | 0 | 0 |
| (4) Dan Lepore | 2.00 | | | | | | | | | |
| Director | | х | | | | | | 0 | 0 | 0 |
| (5) Cass Briggs | 2.00 | | | | | | | | | |
| Director | | х | | | | | | 0 | 0 | 0 |
| (6) Sarah Lepore | 7.00 | | | | | | | | | |
| President | | х | | х | | | | 0 | 0 | 0 |
| (7) Nazira Kelly | 5.00 | | | | | | | | | |
| Vice President | | х | | х | | | | 0 | 0 | 0 |
| (8) Kristen Groseclose | 30.00 | | | | | | | | | |
| Director of Development | | х | | х | | | | 0 | 0 | 0 |
| (9) Mike Groseclose | 15.00 | | | | | | | | | |
| Treasurer and Interim Secretary | | x | | х | | | | 0 | 0 | 0 |
| <u>(10)</u> | | | | | | | | | | |
| | | | | | | | | | | |
| <u>(11)</u> | | | | | | | | | | |
| | | | | | | | | | | |
| <u>(12)</u> | | | | | | | | | | |
| <u>(13)</u> | | | | | | | | | | |
| <u>(14)</u> | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | Earm 000 (2022) |

| Form 9 | | | yndrome | Foun | dat | io | n | | | | | 1-2913 | | | 9age 8 |
|--------------|------------------------------|--|--|--|-----------------------|---------|--------------|---------------------------------|--------|---|---|-----------------------|----------------|--|---------------|
| Part | | Section A. Officers, Directors, 1 | rustees, | Key | Em | - | - | es, ar | nd | Highest Comp | ensated | <u>i Empl</u> | oyees | S (cont | inued) |
| | (A) Name and title | | (B) Average hours per week (list any | Average box, unless person is b officer and a director/truper week | | | | | n | (D) Reportable compensation from the organization (W-2/ | (E) Reporta compensa from rela organization | able ation ated | CO | (F) nated am of other mpensat from the | r |
| | | | hours for related organizations below dotted line) | Individual trustee or director | Institutional trustee | Officer | Key employee | Highest compensated employee | Former | 1099-MISC/ 1099-NEC) | 1099-MI 1099-NE | | • | nization d organiz | |
| (15) | | | | | | | | | | | | | | | |
| (16) | | | | | | | | | | | | | | | |
| <u>(17)</u> | | | | | | | | | | | | | | | |
| <u>(18)</u> | | | | | | | | | | | | | | | |
| <u>(19)</u> | | | | | | | | | | | | | | | |
| <u>(20)</u> | | | | | | | | | | | | | | | |
| <u>(21)</u> | | | | | | | | | | | | | | | |
| <u>(22)</u> | | | | | | | | | | | | | | | |
| <u>(23)</u> | | | | | | | | | | | | | | | |
| <u>(24)</u> | | | | | | | | | | | | | | | |
| (25) | | | | | | | | | | | | | | | |
| 1b c d | | tal | | · · · · · · | ••• | ••• | | | • | 81,865 | | 0 | | | 0 |
| 2 | Total r | number of individuals (including but not limit able compensation from the organization | | | | | | | | | of | | | | |
| 3 | | e organization list any former officer, direct | or, trustee, k | ey em | oloye | e, c | or hig | phest c | com | pensated | | | | Yes | No |
| 4 | | yee on line 1a? <i>If "Yes," complete Schedule</i> ny individual listed on line 1a, is the sum of i | | | | | | | | | | | 3 | | x |
| | - | ization and related organizations greater tha | | | | | | | | | | | 4 | | x |
| 5 | | ny person listed on line 1a receive or accrue rvices rendered to the organization? <i>If</i> "Yes | • | | | - | | | - | | | | 5 | | x |
| Secti | on B. | Independent Contractors | | | | | | | | | | | | | |
| 1 | | lete this table for your five highest compens ensation from the organization. Report com | | | | | | | | | | tax year. | | | |
| | | (A) Name and business addre | ss | | | | | | | (B) Description of servio | es | | (C) Compens | sation | |
| | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | |
| 2 | | number of independent contractors (includir | - | | | se lis | sted | above |) wh | | | | | | |
| | receiv | ed more than \$100,000 of compensation fro | om the orgar | nizatior | ۱ | | | | | | | | | | |

| Form 99 | | | n-Kingsmore | Sync | drome Foundat | ion | | 84-29130 | 37 Page 9 |
|---|---------|--|--------------------------------|----------|------------------------|----------------------|--|--------------------------------------|---|
| Part | VIII | Statement of Rev | | o or n | ata ta any lina in thi | o Dort \/III | | | Г |
| | | Check if Schedule O co | ontains a respons | | | (A) Total revenue | (B) Related or exempt function revenue | (C) Unrelated business revenue | (D) Revenue excluded from tax under |
| | 1a b | Federated campaigns • Membership dues • • • | | 1a 1b | | | | | sections 512–514 |
| ts, Grant Amounts | c d | Fundraising events ••• Related organizations • | | 1c 1d | | | | | |
| Contributions, Gifts, Grants and Other Similar Amounts | f | Government grants (cont All other contributions, gif and similar amounts not i | fts, grants, included above | 1e 1f | 74,563 | | | | |
| Contrik and Ot | g h | Noncash contributions inc lines 1a-1f Total. Add lines 1a-1f | | 1g | \$ | 74,563 | | | |
| | 2 | | | | Business Code | | | | |
| Program Service Revenue | 2a b | | | | | | | | |
| erv ue | c b | | | | | | | | |
| gram Ser Revenue | d | | | | | | | | |
| gra Re | e | | | | | | | | |
| Pro | f | All other program service | revenue | | | | | | |
| | g | Total. Add lines 2a-2f . | | | | | | | |
| | 3 | Investment income (includ other similar amounts) | | | | | | | |
| | 4 | Income from investment of | f tax-exempt bon | d proc | eeds | | | | |
| | 5 | Royalties | · · · · · · · · · | | | | | | |
| | | | (i) Rea | I | (ii) Personal | | | | |
| | | Gross rents | | | | | | | |
| | 1 | Less: rental expenses • • | | | | | | | |
| | 1 | Rental income or (loss) | _[6c] | | | | | | |
| | | Net rental income or (loss) | ́г т | | | | | | |
| | 7a | Gross amount from | (i) Securiti | es | (ii) Other | | | | |
| | | sales of assets other than inventory | 7a | | | | | | |
| | h | Less: cost or other basis | 7a | | | | | | |
| e | | and sales expenses | 76 | | | | | | |
| enu | c | Gain or (loss) | | | | | | | |
| Rev | | Net gain or (loss) | | | | | | | |
| Other Revenue | | Gross income from fundra | | | | | | | |
| đ | | events (not including \$ | | | | | | | |
| | | of contributions reported o | on line | | | | | | |
| | | 1c). See Part IV, line 18 | | 8a | | | | | |
| | | Less: direct expenses . | | 8b | | | | | |
| | | Net income or (loss) from | - | ts 🔒 | | | | | |
| | 9a | Gross income from gaming | - | | | | | | |
| | . | activities, See Part IV, line | | 9a | | | | | |
| | | Less: direct expenses • | | 9b | | | | | |
| | | Net income or (loss) from | | · · | | | | | |
| | 10a | Gross sales of inventory, le returns and allowances . | | 10a | | | | | |
| | h | Less: cost of goods sold | | 102 | | | | | |
| | 1 | Net income or (loss) from | | | 1 | | | | |
| | | | calco or inventory | , | Business Code | | | | |
| s | 11a | Other Income | | | 900099 | 187 | 187 | | |
| nou ue | b | | | | | 107 | 137 | | |
| ella ven | c c | | | | | | | | |
| Miscellanous Revenue | | All other revenue | | | | | | | |
| Σ | | Total. Add lines 11a-11d | | | | 187 | | | |
| | | Total revenue. See instru | | | | 74 750 | 187 | 0 | 0 |

022) Smith-Kingsmore Syndrome Foundation Statement of Functional Expenses

| Sect | ion 501(c)(3) and 501(c)(4) organizations must complete all cc | olumns. All other organi | zations must complete | column (A). | |
|--------|--|--------------------------|-------------------------------|-----------------------|---------------------------|
| | Check if Schedule O contains a response or note to | any line in this Part IX | | | x |
| Do n | ot include amounts reported on lines 6b, 7b, | (A) Total expenses | (B) Program service | (C) Management and | (D) Fundraising |
| 8b, 9 | b, and 10b of Part VIII. | Iotal expenses | expenses | general expenses | expenses |
| 1 | Grants and other assistance to domestic organizations | | | | |
| | and domestic governments. See Part IV, line 21 | 93,764 | 93,764 | | |
| 2 | Grants and other assistance to domestic | | | | |
| | individuals. See Part IV, line 22 • • • • • • • • • • • • • | | | | |
| 3 | Grants and other assistance to foreign | | | | |
| | organizations, foreign governments, and | | | | |
| | foreign individuals. See Part IV, lines 15 and 16 • • • • | | | | |
| 4 | Benefits paid to or for members | | | | |
| 5 | Compensation of current officers, directors, | | | | |
| _ | trustees, and key employees | 81,865 | 28,385 | 14,192 | 39,288 |
| 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 | | | | |
| 8 | Pension plan accruals and contributions (include | | | | |
| ~ | section 401(k) and 403(b) employer contributions) | | | | |
| 9 | Other employee benefits | | 0.070 | 1.050 | |
| 10 | Payroll taxes | 7,823 | 2,352 | 1,956 | 3,515 |
| 11 | Management | | | | |
| a b | | 2 429 | | 002 | 1 605 |
| b c | | 2,428 | | 803 | 1,625 |
| d | | 6,250 | | 6,250 | |
| e | Professional fundraising services. See Part IV, line 17 | | | | |
| f | Investment management fees | | | | |
| g | Other. (If line 11g amount exceeds 10% of line 25, column | | | | |
| y | (A) amount, list line 11g expenses on Schedule O.) | 14,298 | 5,498 | | 8,800 |
| 12 | Advertising and promotion | 14,290 | 5,490 | | 8,800 |
| 13 | Office expenses | 2,238 | 325 | 535 | 1,378 |
| 14 | Information technology | 7,574 | 270 | 1,504 | 5,800 |
| 15 | Royalties | ., | | | 0,000 |
| 16 | | | | | |
| 17 | Travel | 3,670 | 3,670 | | |
| 18 | Payments of travel or entertainment expenses | | - / | | |
| | for any federal, state, or local public officials | | | | |
| 19 | Conferences, conventions, and meetings | 4,088 | 4,088 | | |
| 20 | Interest | | | | |
| 21 | Payments to affiliates | | | | |
| 22 | Depreciation, depletion, and amortization •••••• | | | | |
| 23 | Insurance | 708 | | 708 | |
| 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.) | | | | |
| а | | | | | |
| b | | | | | |
| С | | | | | |
| d | | | | | |
| е | All other expenses | | | | |
| 25 | Total functional expenses. Add lines 1 through 24e | 224,706 | 138,352 | 25,948 | 60,406 |
| 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) | | | | |

| | | Check if Schedule O contains a response or note to any line in this Part X | | | |
|-----------------------------|-----|---|-------------------|-----|-------------|
| | | · · · | (A) | | (B) |
| | | | Beginning of year | | End of year |
| | 1 | Cash - non-interest-bearing | 195,926 | 1 | 309,150 |
| | 2 | Savings and temporary cash investments | | 2 | |
| | 3 | Pledges and grants receivable, net | 400,196 | 3 | 200,000 |
| | 4 | Accounts receivable, net | | 4 | |
| | 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 | |
| s | 7 | Notes and loans receivable, net | | 7 | |
| Assets | 8 | Inventories for sale or use | | 8 | |
| As | 9 | Prepaid expenses and deferred charges | | 9 | |
| | 10a | Land, buildings, and equipment: cost or other | | | |
| | | basis. Complete Part VI of Schedule D 10a | | | |
| | b | Less: accumulated depreciation | | 10c | |
| | 11 | Investments - publicly traded securities | | 11 | |
| | 12 | Investments - other securities. See Part IV, line 11 | | 12 | |
| | 13 | Investments - program-related. See Part IV, line 11 | | 13 | |
| | 14 | Intangible assets | | 14 | |
| | 15 | Other assets. See Part IV, line 11 | | 15 | |
| | 16 | Total assets. Add lines 1 through 15 (must equal line 33) | 596,122 | 16 | 509,150 |
| | 17 | Accounts payable and accrued expenses | | 17 | 62,984 |
| | 18 | Grants payable | | 18 | |
| | 19 | | | 19 | |
| | 20 | Tax-exempt bond liabilities | | 20 | |
| 6 | 21 | | | 21 | |
| Liabilities | 22 | Loans and other payables to any current or former officer, director, | | | |
| ilidi | | trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons | | 22 | |
| Lia | 23 | Secured mortgages and notes payable to unrelated third parties | | 22 | |
| | 23 | Unsecured notes and loans payable to unrelated third parties | | 23 | |
| | 25 | Other liabilities (including federal income tax, payables to related third | | 24 | |
| | 20 | parties, and other liabilities not included on lines 17-24). Complete Part X | | | |
| | | of Schedule D | | 25 | |
| | 26 | Total liabilities. Add lines 17 through 25 | 0 | 26 | 62,984 |
| | | Organizations that follow FASB ASC 958, check here | | | 02,001 |
| es | | and complete lines 27, 28, 32, and 33. | | | |
| anc | 27 | Net assets without donor restrictions | 19,308 | 27 | 294 |
| Bali | 28 | Net assets with donor restrictions | 576,814 | 28 | 445,872 |
| lpu | | Organizations that do not follow FASB ASC 958, check here | | | |
| Fui | | and complete lines 29 through 33. | | | |
| or | 29 | Capital stock or trust principal, or current funds | | 29 | |
| ets | 30 | Paid-in or capital surplus, or land, building, or equipment fund | | 30 | |
| Ass | 31 | Retained earnings, endowment, accumulated income, or other funds | | 31 | |
| Net Assets or Fund Balances | 32 | Total net assets or fund balances | 596,122 | 32 | 446,166 |
| | 33 | Total liabilities and net assets/fund balances | 596,122 | 33 | 509,150 |

Form 990 (2022) Smith-Kingsmore Syndrome Foundation Part X Balance Sheet

84-2913037

EEA

Form 990 (2022)

Page 11

| Form | 990 (2022) Smith-Kingsmore Syndrome Foundation | 84-291303 | 7 | Pa | age 12 | | | |
|------|---|-----------|----------|------|---------------|--|--|--|
| Pa | rt 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 | | 74, | 750 | | | |
| 2 | Total expenses (must equal Part IX, column (A), line 25) | 2 | | 224, | 706 | | | |
| 3 | Revenue less expenses. Subtract line 2 from line 1 O S | | | | | | | |
| 4 | 4 Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) | | | | | | | |
| 5 | Net unrealized gains (losses) on investments | 5 | | | | | | |
| 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 | | 446, | 166 | | | |
| Pa | rt XII Financial Statements and Reporting | | | | | | | |
| | Check if Schedule O contains a response or note to any line in this Part XII | | | | | | | |
| | | | | Yes | No | | | |
| 1 | Accounting method used to prepare the Form 990: 🗌 Cash 🛛 🕱 Accrual 🔲 Other | | | | | | | |
| | If the organization changed its method of accounting from a prior year or checked "Other," explain on | | | | | | | |
| | Schedule O. | | | | | | | |
| 2a | Were the organization's financial statements compiled or reviewed by an independent accountant? | | 2a | x | | | | |
| | 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: | | | | | | | |
| | X Separate basis Consolidated basis Both consolidated and separate basis | | | | | | | |
| b | Were the organization's financial statements audited by an independent accountant? | | 2b | | х | | | |
| | If "Yes," check a box below to indicate whether the financial statements for the year were audited on a | | | | | | | |
| | separate basis, consolidated basis, or both: | | | | | | | |
| | Separate basis Consolidated basis Both consolidated and separate basis | | | | | | | |
| С | 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? | | 2c | x | | | | |
| | If the organization changed either its oversight process or selection process during the tax year, explain on | | | | | | | |
| | Schedule O. | | | | | | | |
| 3a | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the | | | | | | | |
| | Uniform Guidance, 2 C.F.R. Part 200, Subpart F? | | 3a | | х | | | |
| 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 | | 3b | | | | | |
| | | | F | | | | | |

Form 990 (2022)

| SCHEDULE | A |
|------------|---|
| (Form 990) | |

Public Charity Status and Public Support

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

Attach to Form 990 or Form 990-EZ.

| t. | 2022 | | | | | | | |
|------------------|----------------|--|--|--|--|--|--|--|
| | Open to Public | | | | | | | |
| | Inspection | | | | | | | |
| ification number | | | | | | | | |

OMB No. 1545-0047

| Department of the Treasu | iry |
|--------------------------|-----|
| Internal Revenue Service | |

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

| Name | e of the organization | WWW.HS.gov/For | | | | Employer identification | number | | |
|-------|--|--|---------------------------------|--------------------|--------------|---------------------------|--------------------|--|--|
| Smit | th-Kingsmore Syndrome Foun | dation | | | | 84-291303 | 7 | | |
| Par | | | II organizations mus | st comple | ete this p | | | | |
| The c | organization is not a private foundation b | ecause it is: (For lin | nes 1 through 12, check | only one b | ox.) | | | | |
| 1 | A church, convention of churches, c | or association of ch | nurches described in sec | tion 170(b |)(1)(A)(i). | | | | |
| 2 | A school described in section 170 | b)(1)(A)(ii). (Attach | n Schedule E (Form 990) | .) | | | | | |
| 3 | A hospital or a cooperative hospital | service organization | on described in section | 170(b)(1)(A | A)(iii). | | | | |
| 4 | A medical research organization op | erated in conjuncti | on with a hospital descril | bed in sect | ion 170(b) | (1)(A)(iii). Enter the | | | |
| | hospital's name, city, and state: | | | | | | | | |
| 5 | An organization operated for the be | enefit of a college o | r university owned or op | erated by a | governme | ental unit described in | | | |
| | section 170(b)(1)(A)(iv). (Complete | e Part II.) | | | | | | | |
| 6 | A federal, state, or local governmen | nt or governmental | unit described in sectior | n 170(b)(1) | (A)(v). | | | | |
| 7 | $\mathbf X$ An organization that normally receiv | X An organization that normally receives a substantial part of its support from a governmental unit or from the general public | | | | | | | |
| | described in section 170(b)(1)(A)(v | ∕i). (Complete Part | II.) | | | | | | |
| 8 | A community trust described in sec | tion 170(b)(1)(A)(\ | /i). (Complete Part II.) | | | | | | |
| 9 | An agricultural research organizatio | n described in sec | tion 170(b)(1)(A)(ix) op | erated in co | onjunction | with a land-grant colleg | le | | |
| | or university or a non-land-grant co | llege of agriculture | (see instructions). Enter | the name, | city, and s | state of the college or | | | |
| | university: | | | | | | | | |
| 10 | An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.) | | | | | | | | |
| 11 | An organization organized and oper | , | 1 5 | | , | | | | |
| 12 | An organization organized and ope | - | • | | | | | | |
| | one or more publicly supported orga | | | | | | Check | | |
| | the box on lines 12a through 12d th | | | | • | - | | | |
| а | | | • | | - | | ng | | |
| | the supported organization(s) the | | | • | directors | or trustees of the | | | |
| | supporting organization. You m | - | | | | | | | |
| b | | | | | - | ., | 1 | | |
| | control or management of the s | | | persons in | at control o | or manage the supporte | eu | | |
| | organization(s). You must con c | • | | nnoction u | ith and fu | notionally integrated wit | th | | |
| С | its supported organization(s) (s | | | | | | u1, | | |
| d | | , | - | | | | n(s) | | |
| u | that is not functionally integrate | | | | | | | | |
| | requirement (see instructions). | • | • • • | | • | | | | |
| е | | - | | | | I Type II Type III | | | |
| 0 | functionally integrated, or Type | | | | | i, ijpo ii, ijpo iii | | | |
| f | | | | | | | | | |
| g | | | rganization(s). | | | | | | |
| | (i) Name of supported organization | (ii) EIN | (iii) Type of organization | (iv) Is the o | rganization | (v) Amount of monetary | (vi) Amount of | | |
| | | | (described on lines 1-10 | | ir governing | support (see | other support (see | | |
| | | | above (see instructions)) | docum | ient? | instructions) | instructions) | | |
| | | | | Yes | No | | | | |
| (A) | | | | | | | | | |
| (A) | | | | | | | | | |
| (B) | | | | | | | | | |
| | | | | | | | | | |
| (C) |) | | | | | | | | |
| | | | | | | | | | |
| (D) | | | | | | | | | |
| (E) | | | | | | | | | |
| | | | | | | | | | |
| Total | 1 | | | | | 1 | 1 | | |

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

| | e A (Form 990) 2022 Smith-King: | smore Syndr | ome Foundat | tion | | 84-291303 | 7 Page 2 |
|-------|--|------------------|------------------|------------------|-------------------------|-----------------|--|
| Part | | | | | | | |
| | (Complete only if you checked the complete only if you checked the | | | | | | alify under |
| | Part III. If the organization fails t | o qualify und | er the tests lis | sted below, p | lease comple | te Part III.) | |
| Secti | on A. Public Support | | | | | | |
| Calen | dar year (or fiscal year beginning in) | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
| 1 | Gifts, grants, contributions, and | | | | | | |
| | membership fees received. (Do not | | | | | | |
| | include any "unusual grants.") | | 16,863 | 102,521 | 655,233 | 74,563 | 849,180 |
| 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 | | 16,863 | 102,521 | 655,233 | 74,563 | 849,180 |
| 5 | The portion of total contributions by | | 10,005 | 102,321 | 033,233 | 14,303 | 040,100 |
| • | 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) | | | | | | 400 |
| 6 | Public support. Subtract line 5 from line 4 | | | | | | 426 |
| | on B. Total Support | | | | | | 848,754 |
| - | dar year (or fiscal year beginning in) | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
| 7 | Amounts from line 4 | (a) 2010 | | | | | |
| 8 | Gross income from interest, dividends, | | 16,863 | 102,521 | 655,233 | 74,563 | 849,180 |
| 0 | | | | | | | |
| | payments received on securities loans, | | | | | | |
| | rents, royalties, and income from | | | | | | |
| • | | | | | | | |
| 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.) | | | | 481 | 187 | 668 |
| 11 | Total support. Add lines 7 through 10 | | | | | | 849,848 |
| 12 | Gross receipts from related activities, etc | • | , | | | 12 | |
| 13 | First 5 years. If the Form 990 is for the o | • | | | • | | |
| | organization, check this box and stop he | | | | | | <u>x</u> |
| | on C. Computation of Public Suppo | | | | | | |
| 14 | Public support percentage for 2022 (line | • • | - | | | 14 | % |
| 15 | Public support percentage from 2021 Sch | | | | | 15 | % |
| 16a | 33 1/3% support test - 2022. If the organ | | | | | | |
| | box and stop here. The organization qua | | • • • • | - | | | |
| b | 33 1/3% support test - 2021. If the organ | nization did no | t check a box c | on line 13 or 16 | a, and line 15 | is 33 1/3% or ı | more, check |
| | this box and stop here. The organization | qualifies as a | publicly suppo | rted organizati | on | | [] |
| 17a | 10%-facts-and-circumstances test - 20 | 22. If the orga | nization did not | t check a box o | on line 13, 16a | or 16b, and li | ne 14 is |
| | 10% or more, and if the organization mee | ets the facts-ar | nd-circumstanc | es test, check | this box and s t | op here. Expl | ain in |
| | Part VI how the organization meets the fa | acts-and-circur | nstances test. | The organizati | on qualifies as | a publicly sup | ported |
| | organization | | | | | | Г |
| b | 10%-facts-and-circumstances test - 20 | | | | on line 13, 16a | 16b, or 17a. a | and line |
| | 15 is 10% or more, and if the organization | - | | | | | |
| | in Part VI how the organization meets the | | | | | - | |
| | organization | | | - | | | ··· · · · · · · · · · · · · · · · · · · |
| 18 | Private foundation. If the organization d | | | | a, or 17b. checl | k this box and | see |
| - | instructions | | | | | | |
| | | | | | | | |

| Schedu | le A (Form 990) 2022 Smith-Kings | more Syndr | ome Foundat | cion | | 84-2913 | 037 Page 3 |
|--------|---|----------------------|-------------------|--------------------|--------------------|---------------|----------------|
| Part | | | | | | | |
| | (Complete only if you checked th | | | | | | under Part II. |
| | If the organization fails to qualify | under the te | sts listed belo | ow, please co | omplete Part I | l.) | |
| Secti | on A. Public Support | | | | | | |
| Calen | dar year (or fiscal year beginning in) | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (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 | | | | | | |
| /a | Amounts included on lines 1, 2, and 3 | | | | | | |
| h. | 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 Add lines 7a and 7b | | | | | | |
| с 8 | Public support. (Subtract line 7c from | | | | | | |
| 0 | | | | | | | |
| Socti | line 6.) | | | | | | |
| | dar year (or fiscal year beginning in) | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
| 9 | Amounts from line 6 | (a) 2010 | (b) 2013 | (0) 2020 | (u) 2021 | (6) 2022 | |
| 10a | Gross income from interest, dividends, | | | | | | |
| ivu | 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 | | | | | | |
| с | 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 or | ganization's fi | rst, second, th | ird, fourth, or fi | fth tax year as | a section 5 | 01(c)(3) |
| | organization, check this box and stop her | е | | | | | |
| Secti | on C. Computation of Public Suppo | | | | | | |
| 15 | Public support percentage for 2022 (line 8 | 3, column (f), c | livided by line | 13, column (f)) | | 15 | % |
| 16 | Public support percentage from 2021 Sch | | | | | 16 | % |
| Secti | on D. Computation of Investment In | come Perce | ntage | | | | |
| 17 | Investment income percentage for 2022 (| line 10c, colun | nn (f), divided b | oy line 13, colu | ımn (f)) | 17 | % |
| 18 | Investment income percentage from 2021 | Schedule A, | Part III, line 17 | | | 18 | % |
| 19a | 33 1/3% support tests - 2022. If the orga | nization did no | ot check the bo | ox on line 14, a | nd line 15 is m | ore than 33 | 1/3%, and line |
| | 17 is not more than 33 1/3%, check this b | ox and stop h | ere. The organ | nization qualifie | es as a publicly | supported | organization |
| b | 33 1/3% support tests - 2021. If the organization | n did not check | a box on line 14 | or line 19a, and l | ine 16 is more tha | an 33 1/3%, a | ind |
| | line 18 is not more than 33 1/3%, check this box | • | - | • • | • • • • | - | 🗌 |
| 20 | Private foundation. If the organization di | d not check a | box on line 14, | , 19a, or 19b, c | check this box a | and see inst | tructions |

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of 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

- 1 Are all of the organization's supported organizations listed by name in the organization's governing documents? *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.*
- 2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in **Part VI** how the organization determined that the supported organization was described in section 509(a)(1) or (2).
- **3a** Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? *If "Yes," answer lines 3b and 3c below.*
- **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)? *If "Yes," describe in Part VI when and how the organization made the determination.*
- c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in **Part VI** what controls the organization put in place to ensure such use.
- **4a** Was any supported organization not organized in the United States ("foreign supported organization")? *If* "Yes," and if you checked 12a or 12b in Part I, answer lines 4b and 4c below.
- **b** Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? 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.
- **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)? *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.*
- 5a Did the organization add, substitute, or remove any supported organizations during the tax year? 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).
- **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? *If "Yes," provide detail in Part VI.*
- 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? *If "Yes," complete Part I of Schedule L (Form 990).*
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).
- **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))? *If "Yes," provide detail in Part VI.*
- **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? *If "Yes," provide detail in Part VI.*
- **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? *If "Yes," provide detail in Part VI.*
- **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)? *If "Yes," answer 10b below.*
 - **b** Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)

No

Yes

1

2

3a

3b

3c

4a

4b

4c

5a

5b

5c

6

7

8

9a

9b

9c

10a

10b

| | | | 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 | | | |
| a | 11c below, the governing body of a supported organization? | 11a | | |
| | | | | |
| b | A family member of a person described on line 11a above? | 11b | | |
| С | A 35% controlled entity of a person described on 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, | | | |
| ;; | provide detail in Part VI. | 11c | | |
| Secti | on 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. | 1 | | |
| 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 | | | |
| | <i>VI</i> how providing such benefit carried out the purposes of the supported organization(s) that operated, | | | |
| | supervised, or controlled the supporting organization. | 2 | | |
| Socti | on C. Type II Supporting Organizations | 2 | | |
| Secu | | | Vee | Na |
| | | | 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 | | |
| Secti | on 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? | 1 | | |
| 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). | 2 | | |
| 3 | By reason of the relationship described in 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. | 3 | | |
| Secti | on E. Type III Functionally Integrated Supporting Organizations | <u> </u> | | |
| 1 | Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (se | ina | | <u> </u> |
| | | 3 11151 | ucu | unsj. |
| a b | The organization satisfied the Activities Test. <i>Complete line 2 below.</i> | | | |
| b | The organization is the parent of each of its supported organizations. <i>Complete line 3 below</i> . | | | |
| c | The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instruction Activities Test. 1 and 2 and 2 be to be to be | ns). | V | |
| 2 | Activities Test. Answer lines 2a and 2b below. | | Yes | No |
| а | 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. | 2a | | |
| 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. | 2b | | |
| 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. | 3a | | |
| 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. | 3b | | |
| | Schedul | | orm 00 | 0) 2022 |
| EEA | Schedul | ~ ~ (F) | | -, 2022 |

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 Schedule A (Form 990) 2022
 Smith-Kingsmore
 Syndrome
 Foundation

 Part IV
 Supporting Organizations (continued)
 Foundation
 Fo

| Part | V Type III Non-Functionally Integrated 509(a)(3) Supporting Or | gar | nizations | |
|-------|---|-------|---------------------------------|--------------------------------|
| 1 [|] Check here if the organization satisfied the Integral Part Test as a qualifying | g tru | st on Nov. 20, 1970 <i>(exp</i> | lain in Part VI). See |
| | instructions. All other Type III non-functionally integrated supporting organ | nizat | ions must complete Sect | ions A through E. |
| Secti | on 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 | | |
| Secti | on 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): | | | |
| а | Average monthly value of securities | 1a | | |
| b | Average monthly cash balances | 1b | | |
| С | Fair market value of other non-exempt-use assets | 1c | | |
| d | Total (add lines 1a, 1b, and 1c) | 1d | | |
| е | 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 | | |
| Secti | on 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 | • | - | ntegrated Type III suppor | ting organization |

Smith-Kingsmore Syndrome Foundation

Schedule A (Form 990) 2022

Schedule A (Form 990) 2022

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| | e A (Form 990) 2022 Smith-Kingsmore Syndrome | Foundation | 84-2 | 2913 | 037 Page 7 |
|---------------|--|------------------------------------|---------------------------------------|------|---|
| Part | V Type III Non-Functionally Integrated 509(a)(| Supporting Organ | izations (continue | ed) | |
| Secti | on D - Distributions | | | | Current Year |
| 1 | Amounts paid to supported organizations to accomplish e | exempt purposes | | 1 | |
| 2 | Amounts paid to perform activity that directly furthers exe | mpt purposes of suppor | ted | | |
| | organizations, in excess of income from activity | | | 2 | |
| 3 | Administrative expenses paid to accomplish exempt purp | oses of supported orgar | nizations | 3 | |
| 4 | Amounts paid to acquire exempt-use assets | | | 4 | |
| 5 | Qualified set-aside amounts (prior IRS approval required) | | t 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 | n the organization is resp | ponsive | | |
| | (provide details in Part VI). See instructions. | | | 8 | |
| 9 | Distributable amount for 2022 from Section C, line 6 | | | 9 | |
| 10 | Line 8 amount divided by line 9 amount | | | 10 | |
| Secti | on E - Distribution Allocations (see instructions) | (i) Excess Distributions | (ii) Underdistributior Pre-2022 | ns | (iii) Distributable Amount for 2022 |
| 1 | Distributable amount for 2022 from Section C, line 6 | | | | |
| 2 | Underdistributions, if any, for years prior to 2022 | | | | |
| | (reasonable cause required - <i>explain in Part VI</i>). See | | | | |
| | instructions. | | | | |
| 3 | Excess distributions carryover, if any, to 2022 | | | | |
| a | From 2017 | | | | |
| b | From 2018 | | | | |
| C | From 2019 | | | | |
| d | From 2020 | | | | |
| e | From 2021 | | | | |
| f | Total of lines 3a through 3e | | | | |
| | Applied to underdistributions of prior years | | | _ | |
| | Applied to 2022 distributable amount | | | | |
| i | Carryover from 2017 not applied (see instructions) | | | | |
| | Remainder. Subtract lines 3g, 3h, and 3i from line 3f. | | | | |
| 4 | Distributions for 2022 from | | | | |
| | Section D, line 7: \$ | | | | |
| | Applied to underdistributions of prior years | | | | |
| b | | | | | |
| <u> </u> | Remainder. Subtract lines 4a and 4b from line 4. | | | _ | |
| 5 | Remaining underdistributions for years prior to 2022, if | | | | |
| | any. Subtract lines 3g and 4a from line 2. For result | | | | |
| | greater than zero, <i>explain in Part VI</i> . See instructions. Remaining underdistributions for 2022. Subtract lines 3h | | | _ | |
| 6 | - | | | | |
| | and 4b from line 1. For result greater than zero, <i>explain in</i> | | | | |
| | Part VI. See instructions. | | | _ | |
| 7 | Excess distributions carryover to 2023. Add lines 3j | | | | |
| 8 | and 4c. Breakdown of line 7: | | | | |
| - | F (0010 | | | | |
| <u>a</u> b | E | | | | |
| <u> </u> | F (0000 | | | | |
| d | E | | | | |
| e | Excess from 2021 Excess from 2022 | | | | |
| EEA | | | | s | Schedule A (Form 990) 2022 |
| • | | | | | |

| Part VI | Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part II, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.) |
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| SCHEDULE I Grants and Other Assistance to Organizations, (Form 990) Governments, and Individuals in the United States Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22. | | | | | | | F | OMB No. 1545-0047 |
|--|---------------------------|----------------------------|---------------------------------|--|------------------------------|---|--------------------|----------------------|
| Department of the Treasury | | Complet | te if the organization a | nswered "Yes" on Fo Attach to Form 990. | rm 990, Part IV, line 21 | or 22. | Open to Public | |
| Internal Revenue Service Go to www.irs.gov/Form990 for the latest information. | | | | | | | | Inspection |
| Name of the organization Employer identification | | | | | | | | |
| Smith-Kingsmore | Syndrome Found | ation | | | | | 84-2913037 | , |
| | | Grants and Assi | | | | | | |
| 1 Does the organizati | on maintain records to | o substantiate the amo | ount of the grants or ass | istance, the grantees' e | eligibility for the grants o | r assistance, and | | |
| | 0 | | | | | | | . <u>x</u> Yes No |
| 2 Describe in Part IV | the organization's pro | cedures for monitoring | the use of grant funds | in the United States. | | | | |
| | | | | | | organization answered | I "Yes" on Form 9 | 90, |
| | , , , | | ore than \$5,000. Pa | · · · | ed if additional space | | 1 | |
| 1 (a) Name and addres | | (b) EIN | (c) IRC section | (d) Amount of cash | (e) Amount of | (f) Method of valuation (book, FMV, appraisal, | (g) Description of | (h) Purpose of grant |
| or govern | | | (if applicable) | grant | noncash assistance | other) | noncash assistance | or assistance |
| (1) University of | Florida Found | | | | | | | |
| PO Box 14425 | 2604 | 50 0074700 | F01 (-) (2) | 20.700 | | | | |
| Gainesville FL 32 | | 59-0974739 | 501(c)(3) | 30,780 | | | | Research |
| (2) Regents of Uni | | | | | | | | |
| 1850 Research Par | rk Drive | 04 6026404 | F01 (-) (2) | CO. 004 | | | | |
| Davis CA 95618 | | 94-6036494 | 501(c)(3) | 62,984 | | | | Research |
| (3) | | | | | | | | |
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| (4) | | | | | | | | |
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| (10) | | | | | | | | |
| (10) | | | | | | | | |
| | | | | | | | | |
| 2 Enter total number | of section $501(c)(3)$ as | I nd government organi: | I zations listed in the line | 1 table | <u> </u> | | <u> </u> | |
| | | • | | | | | - | 2 |

Schedule I (Form 990) (2022) Smith-Kingsmore Syndrome Foundation

| 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 noncash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance | | |
| | | | | | | | | |

| 3 | | | | | | | | |
|------|---|--|--|--|--|--|--|--|
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| 6 | | | | | | | | |
| | | | | | | | | |
| 7 | | | | | | | | |
| Part | Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information. | | | | | | | |

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2

SCHEDULE O (Form 990)

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

Open to Public Inspection

Employer identification number

84-2913037

Department of the Treasury Internal Revenue Service

Name of the organization

Smith-Kingsmore Syndrome Foundation

01. Officer, directors, etc. family relationship (Part VI, line 2)

There are members of the Board of Directors that have family relationships.

02. Form 990 governing body review (Part VI, line 11)

The IRS Form 990 is prepared by an independent CPA and is reviewed in detail with the

Treasurer before providing to the Board for review.

03. Conflict of interest policy compliance (Part VI, line 12c)

The Organization has a conflict of interest policy that requires the disclosure of

conflicts of interest, including potential and perceived conflicts. A conflicted board

member would be recused regarding the matter where the member has a potential or perceived

conflict of interest.

04. Governing documents, etc, available to public (Part VI, line 19)

These documents are available upon request.

05. List of other fees for services expenses (Part IX, line 11g)

Other Consultants \$14,298