

# Return of Organization Exempt From Income Tax

**2021**

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

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

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

**A** For the 2021 calendar year, or tax year beginning **07-01**, 2021, and ending **06-30**, 2022

**B** Check if applicable:  
 Address change  
 Name change  
 Initial return  
 Final return/terminated  
 Amended return  
 Application pending

**C** Name of organization **Smith-Kingsmore Syndrome Foundation**  
 Doing business as \_\_\_\_\_  
 Number and street (or P.O. box if mail is not delivered to street address) Room/suite  
**5903 Franklin Trl**  
 City or town, state or province, country, and ZIP or foreign postal code  
**Liberty Twp, OH 45011**

**D** Employer identification number  
**84-2913037**

**E** Telephone number  
**(513) 755-1705**

**F** Name and address of principal officer: **Kristen Groseclose**  
**Same as C above**

**G** Gross receipts  
 \$ **655,714**

**H(a)** Is this a group return for subordinates?  Yes  No  
**H(b)** Are all subordinates included?  Yes  No  
 If "No," attach a list. See instructions

**I** Tax-exempt status:  501(c)(3)  501(c) ( ) (insert no.)  4947(a)(1) or  527

**J** Website: ▶ **https://smithkingsmore.org**

**K** Form of organization:  Corporation  Trust  Association  Other ▶

**L** Year of formation: **2019** **M** State of legal domicile: **OH**

**H(c)** Group exemption number ▶

**Part I Summary**

<b>Activities &amp; Governance</b>	1 Briefly describe the organization's mission or most significant activities: <b>Fund research of Smith-Kingsmore syndrome by providing grants to researchers and research institutions.</b>			
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.			
	3	Number of voting members of the governing body (Part VI, line 1a)	8	
	4	Number of independent voting members of the governing body (Part VI, line 1b)	8	
	5	Total number of individuals employed in calendar year 2021 (Part V, line 2a)	0	
	6	Total number of volunteers (estimate if necessary)	20	
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	0	
	7b	Net unrelated business taxable income from Form 990-T, Part I, line 11	0	
<b>Revenue</b>			Prior Year	Current Year
	8	Contributions and grants (Part VIII, line 1h)	102,521	655,233
	9	Program service revenue (Part VIII, line 2g)		0
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)		0
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		481
12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	102,521	655,714	
<b>Expenses</b>	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	88,852	58,853
	14	Benefits paid to or for members (Part IX, column (A), line 4)		0
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		0
	16a	Professional fundraising fees (Part IX, column (A), line 11e)		600
	b	Total fundraising expenses (Part IX, column (D), line 25) ▶	16,598	
	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	4,162	24,740
18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	93,014	84,193	
19	Revenue less expenses. Subtract line 18 from line 12	9,507	571,521	
<b>Net Assets or Fund Balances</b>			Beginning of Current Year	End of Year
	20	Total assets (Part X, line 16)	24,815	596,122
	21	Total liabilities (Part X, line 26)	214	0
22	Net assets or fund balances. Subtract line 21 from line 20	24,601	596,122	

**Part II Signature Block**

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

**Sign Here**

▶ Kristen Groseclose  
Signature of officer

▶ Kristen Groseclose, President  
Type or print name and title

Date

**Paid Preparer Use Only**

Print/Type preparer's name: **John Mullins** Preparer's signature: **John Mullins** Date: **11-09-2022**

Check  if PTIN self-employed **P01429307**

Firm's name ▶ **Mullins, PC** Firm's EIN ▶

Firm's address ▶ **7625 Wisconsin Avenue** Phone no. **202-770-6371**  
**Bethesda MD 20814**

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

For Paperwork Reduction Act Notice, see the separate instructions.

**Part III Statement of Program Service Accomplishments**

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

1 Briefly describe the organization's mission:

**Fund research of Smith-Kingsmore syndrome by providing grants to researchers and research institutions.**

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?  Yes  No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?  Yes  No

If "Yes," describe these changes on Schedule O.

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

4a (Code: ) (Expenses \$ **66,703** including grants of \$ **58,853**) (Revenue \$ )

**This year, Smith-Kingsmore Syndrome Foundation (SKSF) has funded a 3rd year of Smith-Kingsmore syndrome (SKS) foundational research at the University of Florida in Dr. Liu's research lab, bringing its total investment in this work to \$178,485. This initial 3-year SKSF investment will spark larger research funding. SKSF collaborated with its Medical & Scientific Advisory (MSA) to produce the SKS Report for NORD's Rare Disease Database and patient information brochure, providing critical information for both medical professionals and family members in the SKS community. In addition, SKS increased engagement through campaigns for Awareness Day and Rare Disease Day, connecting medical experts with families, and collaborating with other rare disease advocacy organizations.**

4b (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )

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 **66,703**

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1 through 21, with sub-questions a-f for questions 4, 11, 12, and 14. 'X' marks are present in the Yes or No columns for various questions.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question, Yes, No. Rows 22-38 covering various organizational requirements and financial reporting.

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with 3 columns: Question, Yes, No. Rows 1a-1c regarding Form 1096, Form W-2G, and backup withholding rules.

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)		Yes	No		
<b>2a</b>	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	0		
<b>b</b>	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? . . . . .	<b>2b</b>		X	
<b>Note:</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.					
<b>3a</b>	Did the organization have unrelated business gross income of \$1,000 or more during the year? . . . . .	<b>3a</b>			X
<b>b</b>	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O . . . . .	<b>3b</b>			
<b>4a</b>	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)? . . . . .	<b>4a</b>			X
<b>b</b>	If "Yes," enter the name of the foreign country <input type="checkbox"/> _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).				
<b>5a</b>	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . . . . .	<b>5a</b>			X
<b>b</b>	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? . . . . .	<b>5b</b>			X
<b>c</b>	If "Yes" to line 5a or 5b, did the organization file Form 8886-T? . . . . .	<b>5c</b>			
<b>6a</b>	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? . . . . .	<b>6a</b>			X
<b>b</b>	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? . . . . .	<b>6b</b>			
<b>7</b>	<b>Organizations that may receive deductible contributions under section 170(c).</b>				
<b>a</b>	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? . . . . .	<b>7a</b>			X
<b>b</b>	If "Yes," did the organization notify the donor of the value of the goods or services provided? . . . . .	<b>7b</b>			
<b>c</b>	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? . . . . .	<b>7c</b>			X
<b>d</b>	If "Yes," indicate the number of Forms 8282 filed during the year . . . . .	<b>7d</b>			
<b>e</b>	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? . . . . .	<b>7e</b>			X
<b>f</b>	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . . . .	<b>7f</b>			X
<b>g</b>	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? . . . . .	<b>7g</b>			
<b>h</b>	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? . . . . .	<b>7h</b>			
<b>8</b>	<b>Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year? . . . . .	<b>8</b>			
<b>9</b>	<b>Sponsoring organizations maintaining donor advised funds.</b>				
<b>a</b>	Did the sponsoring organization make any taxable distributions under section 4966? . . . . .	<b>9a</b>			
<b>b</b>	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . . . .	<b>9b</b>			
<b>10</b>	<b>Section 501(c)(7) organizations.</b> Enter:				
<b>a</b>	Initiation fees and capital contributions included on Part VIII, line 12 . . . . .	<b>10a</b>			
<b>b</b>	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities . . . . .	<b>10b</b>			
<b>11</b>	<b>Section 501(c)(12) organizations.</b> Enter:				
<b>a</b>	Gross income from members or shareholders . . . . .	<b>11a</b>			
<b>b</b>	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.) . . . . .	<b>11b</b>			
<b>12a</b>	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041? . . . . .	<b>12a</b>			
<b>b</b>	If "Yes," enter the amount of tax-exempt interest received or accrued during the year . . . . .	<b>12b</b>			
<b>13</b>	<b>Section 501(c)(29) qualified nonprofit health insurance issuers.</b>				
<b>a</b>	Is the organization licensed to issue qualified health plans in more than one state? . . . . .	<b>13a</b>			
<b>Note:</b> See the instructions for additional information the organization must report on Schedule O.					
<b>b</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 . . . . .	<b>13b</b>			
<b>c</b>	Enter the amount of reserves on hand . . . . .	<b>13c</b>			
<b>14a</b>	Did the organization receive any payments for indoor tanning services during the tax year? . . . . .	<b>14a</b>			X
<b>b</b>	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O . . . . .	<b>14b</b>			
<b>15</b>	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? . . . . .	<b>15</b>			X
If "Yes," see instructions and file Form 4720, Schedule N.					
<b>16</b>	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? . . . . .	<b>16</b>			X
If "Yes," complete Form 4720, Schedule O.					
<b>17</b>	<b>Section 501(c)(21) organizations.</b> Did the trust, any disqualified person, or mine operator engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? . . . . .	<b>17</b>			
If "Yes," complete Form 6069.					

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

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

Section A. Governing Body and Management

Table with 5 columns: Question, 1a, 1b, Yes, No. Rows include questions about voting members, family relationships, and governance decisions.

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

Table with 5 columns: Question, Yes, No. Rows include questions about local chapters, conflict of interest policies, whistleblower policies, and compensation review.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed Statement #17
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.
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

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, 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.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations W-2/ 1099-MISC/ 1099-NEC	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) <u>Eric Kelly</u> Director	5.00	X						0	0	0
(2) <u>Matt Walsh</u> Director	1.00	X						0	0	0
(3) <u>Cass Briggs</u> Director	2.00	X						0	0	0
(4) <u>Dan Lepore</u> Director	2.00	X						0	0	0
(5) <u>Nazira Kelly</u> Vice Chair Medical Advisory	5.00	X		X				0	0	0
(6) <u>Sarah Lepore</u> Vice President, Chair Medical Advis	7.00	X		X				0	0	0
(7) <u>Kristen Groseclose</u> President	30.00	X		X				0	0	0
(8) <u>Mike Groseclose</u> Treasurer and Interim Secretary	15.00	X		X				0	0	0
(9) -----										
(10) -----										
(11) -----										
(12) -----										
(13) -----										
(14) -----										

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(15) -----	-----									
(16) -----	-----									
(17) -----	-----									
(18) -----	-----									
(19) -----	-----									
(20) -----	-----									
(21) -----	-----									
(22) -----	-----									
(23) -----	-----									
(24) -----	-----									
(25) -----	-----									
<b>1b Subtotal</b> .....										
<b>c Total from continuation sheets to Part VII, Section A</b> .....										
<b>d Total (add lines 1b and 1c)</b> .....							0	0	0	

**2** Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization **0**

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

**Section B. Independent Contractors**

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

(A) Name and business address	(B) Description of services	(C) Compensation

**2** Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization **0**



**Part VIII Statement of Revenue**

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
<b>Contributions, Gifts, Grants and Other Similar Amounts</b>	<b>1a</b> Federated campaigns . . . . .	<b>1a</b>					
	<b>b</b> Membership dues . . . . .	<b>1b</b>					
	<b>c</b> Fundraising events . . . . .	<b>1c</b>					
	<b>d</b> Related organizations . . . . .	<b>1d</b>					
	<b>e</b> Government grants (contributions) . .	<b>1e</b>					
	<b>f</b> All other contributions, gifts, grants, and similar amounts not included above	<b>1f</b>	655,233				
	<b>g</b> Noncash contributions included in lines 1a-1f . . . . .	<b>1g</b>	\$				
	<b>h Total.</b> Add lines 1a-1f . . . . .			655,233			
<b>Program Service Revenue</b>			Business Code				
	<b>2a</b> _____						
	<b>b</b> _____						
	<b>c</b> _____						
	<b>d</b> _____						
	<b>e</b> _____						
	<b>f</b> All other program service revenue . . . . .						
<b>g Total.</b> Add lines 2a-2f . . . . .							
<b>Other Revenue</b>	<b>3</b> Investment income (including dividends, interest, and other similar amounts) . . . . .						
	<b>4</b> Income from investment of tax-exempt bond proceeds . . . . .						
	<b>5</b> Royalties . . . . .						
	<b>6a</b> Gross rents . . . . .		(i) Real	(ii) Personal			
			<b>6a</b>				
			<b>6b</b>				
	<b>c</b> Rental income or (loss)	<b>6c</b>					
	<b>d</b> Net rental income or (loss) . . . . .						
	<b>7a</b> Gross amount from sales of assets other than inventory		(i) Securities	(ii) Other			
			<b>7a</b>				
			<b>7b</b>				
	<b>c</b> Gain or (loss) . . . . .	<b>7c</b>					
	<b>d</b> Net gain or (loss) . . . . .						
	<b>8a</b> Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18 . . . . .						
			<b>8a</b>				
<b>8b</b>							
<b>c</b> Net income or (loss) from fundraising events . . . . .							
<b>9a</b> Gross income from gaming activities, See Part IV, line 19 . . . . .							
		<b>9a</b>					
		<b>9b</b>					
<b>c</b> Net income or (loss) from gaming activities . . . . .							
<b>10a</b> Gross sales of inventory, less returns and allowances . . . . .							
		<b>10a</b>					
		<b>10b</b>					
<b>c</b> Net income or (loss) from sales of inventory . . . . .							
<b>Miscellaneous Revenue</b>			Business Code				
	<b>11a Other</b> _____		900099	481	481		
	<b>b</b> _____						
	<b>c</b> _____						
	<b>d</b> All other revenue . . . . .						
<b>e Total.</b> Add lines 11a-11d . . . . .			481				
<b>12 Total revenue.</b> See instructions . . . . .			655,714	481	0	0	

**Part IX Statement of Functional Expenses**

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

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

<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 . . . .	58,853	58,853		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22 . . . . .				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 . . . . .				
<b>4</b> Benefits paid to or for members . . . . .				
<b>5</b> Compensation of current officers, directors, trustees, and key employees . . . . .				
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) . . . . .				
<b>7</b> Other salaries and wages . . . . .				
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) . . . . .				
<b>9</b> Other employee benefits . . . . .				
<b>10</b> Payroll taxes . . . . .				
<b>11</b> Fees for services (nonemployees):				
<b>a</b> Management . . . . .				
<b>b</b> Legal . . . . .	1,573			1,573
<b>c</b> Accounting . . . . .				
<b>d</b> Lobbying . . . . .				
<b>e</b> Professional fundraising services. See Part IV, line 17 . . . . .	600			600
<b>f</b> Investment management fees . . . . .				
<b>g</b> Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.) . . . . .	20,950	7,500		13,450
<b>12</b> Advertising and promotion . . . . .				
<b>13</b> Office expenses . . . . .	1,411	350	185	876
<b>14</b> Information technology . . . . .	312		213	99
<b>15</b> Royalties . . . . .				
<b>16</b> Occupancy . . . . .				
<b>17</b> Travel . . . . .				
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials . . . . .				
<b>19</b> Conferences, conventions, and meetings . . . . .				
<b>20</b> Interest . . . . .				
<b>21</b> Payments to affiliates . . . . .				
<b>22</b> Depreciation, depletion, and amortization . . . . .				
<b>23</b> Insurance . . . . .	494		494	
<b>24</b> 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.)				
<b>a</b> _____				
<b>b</b> _____				
<b>c</b> _____				
<b>d</b> _____				
<b>e</b> All other expenses _____				
<b>25 Total functional expenses.</b> Add lines 1 through 24e . . . . .	84,193	66,703	892	16,598
<b>26 Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) . . . . .				

**Part X Balance Sheet**

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

		(A)		(B)
		Beginning of year		End of year
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing	23,989	1	195,926
	<b>2</b> Savings and temporary cash investments		2	
	<b>3</b> Pledges and grants receivable, net	826	3	400,196
	<b>4</b> Accounts receivable, net		4	
	<b>5</b> 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	
	<b>6</b> 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	
	<b>7</b> Notes and loans receivable, net		7	
	<b>8</b> Inventories for sale or use		8	
	<b>9</b> Prepaid expenses and deferred charges		9	
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a		
	<b>b</b> Less: accumulated depreciation	10b		10c
	<b>11</b> Investments - publicly traded securities		11	
	<b>12</b> Investments - other securities. See Part IV, line 11		12	
	<b>13</b> Investments - program-related. See Part IV, line 11		13	
	<b>14</b> Intangible assets		14	
	<b>15</b> Other assets. See Part IV, line 11		15	
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33)		24,815	16	596,122
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses	214	17	
	<b>18</b> Grants payable		18	
	<b>19</b> Deferred revenue		19	
	<b>20</b> Tax-exempt bond liabilities		20	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties		23	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties		24	
	<b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		25	
	<b>26 Total liabilities.</b> Add lines 17 through 25		214	26
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions	23,601	27	19,308
	<b>28</b> Net assets with donor restrictions	1,000	28	576,814
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds		29	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund		30	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		31	
	<b>32</b> Total net assets or fund balances	24,601	32	596,122
<b>33</b> Total liabilities and net assets/fund balances	24,815	33	596,122	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	655,714
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	84,193
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	571,521
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	24,601
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain on Schedule O)	<b>9</b>	0
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	<b>10</b>	596,122

**Part XII Financial Statements and Reporting**

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

		Yes	No
<b>1</b>	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
<b>2a</b>	Were the organization's financial statements compiled or reviewed by an independent accountant? . . . . . If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	x	
<b>b</b>	Were the organization's financial statements audited by an independent accountant? . . . . . If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		x
<b>c</b>	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? . . . . . If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	x	
<b>3a</b>	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? . . . . .		x
<b>b</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 . . . . .		

**SCHEDULE A  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2021**

**Open to Public  
Inspection**

<b>Name of the organization</b> Smith-Kingsmore Syndrome Foundation	<b>Employer identification number</b> 84-2913037
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**Part I Reason for Public Charity Status.** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2  A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990).)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9  An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and 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 operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
  - a  **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
  - b  **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
  - c  **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
  - d  **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
  - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
- f Enter the number of supported organizations . . . . .
- g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
<b>Total</b>						

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

Section A. Public Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished by a governmental unit; 4 Total. Add lines 1 through 3; 5 The portion of total contributions by each person; 6 Public support. Subtract line 5 from line 4.

Section B. Total Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 9 Net income from unrelated business activities; 10 Other income; 11 Total support. Add lines 7 through 10; 12 Gross receipts from related activities; 13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here.

Section C. Computation of Public Support Percentage

Table with 3 columns: Line number, Description, and Percentage. Rows include: 14 Public support percentage for 2021; 15 Public support percentage from 2020 Schedule A, Part II, line 14; 16a 33 1/3% support test - 2021; b 33 1/3% support test - 2020; 17a 10%-facts-and-circumstances test - 2021; b 10%-facts-and-circumstances test - 2020; 18 Private foundation.

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

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

Section A. Public Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included on line 10b; 12 Other income. Do not include gain or loss from the sale of capital assets; 13 Total support. (Add lines 9, 10c, 11, and 12.)

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

Section C. Computation of Public Support Percentage

Table with 2 columns: Description, Percentage. Row 15: Public support percentage for 2021 (line 8, column (f), divided by line 13, column (f)) 15%. Row 16: Public support percentage from 2020 Schedule A, Part III, line 15 16%.

Section D. Computation of Investment Income Percentage

Table with 2 columns: Description, Percentage. Row 17: Investment income percentage for 2021 (line 10c, column (f), divided by line 13, column (f)) 17%. Row 18: Investment income percentage from 2020 Schedule A, Part III, line 17 18%.

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

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

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

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

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



**Part IV Supporting Organizations (continued)**

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

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> 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? <i>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.</i>		
	<b>1</b>	
<b>2</b> 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? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.</i>		
	<b>2</b>	

**Section C. Type II Supporting Organizations**

	Yes	No
<b>1</b> 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)? <i>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).</i>		
	<b>1</b>	

**Section D. All Type III Supporting Organizations**

	Yes	No
<b>1</b> 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?		
	<b>1</b>	
<b>2</b> 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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
	<b>2</b>	
<b>3</b> 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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		
	<b>3</b>	

**Section E. Type III Functionally Integrated Supporting Organizations**

<b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
<b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.			
<b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.			
<b>c</b> <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).			
<b>2</b> Activities Test. Answer lines 2a and 2b below.		<b>Yes</b>	<b>No</b>
<b>a</b> 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? <i>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.</i>			
	<b>2a</b>		
<b>b</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? <i>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.</i>			
	<b>2b</b>		
<b>3</b> Parent of Supported Organizations. Answer lines 3a and 3b below.			
<b>a</b> 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? <i>If "Yes" or "No," provide details in Part VI.</i>			
	<b>3a</b>		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>			
	<b>3b</b>		

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

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

<b>Section A - Adjusted Net Income</b>		(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	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	8	

<b>Section B - Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):		
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	<b>Minimum Asset Amount</b> (add line 7 to line 6)	8	

<b>Section C - Distributable Amount</b>			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	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	
7	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

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

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

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



**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

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

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

▶ Attach to Form 990.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2021**

**Open to Public  
Inspection**

Name of the organization

Employer identification number

Smith-Kingsmore Syndrome Foundation

**84-2913037**

**Part I General Information on Grants and Assistance**

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

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

1	(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1)	University of Florida Found PO Box 14425 Gainesville FL 32604	59-0974739	501 (c) (3)	58,852				Research
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								
(10)								

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

**Part III Grants and Other Assistance to 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
1					
2					
3					
4					
5					
6					
7					

**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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**SCHEDULE O  
(Form 990)**

**Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

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

**2021**

Department of the Treasury  
Internal Revenue Service

▶ Attach to Form 990 or Form 990-EZ.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

**Open to Public  
Inspection**

Name of the organization

**Smith-Kingsmore Syndrome Foundation**

Employer identification number

**84-2913037**

**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 \$20,950