

Short Form

Return of Organization Exempt From Income Tax

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

2020

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

▶ Go to www.irs.gov/Form990EZ for instructions and the latest information.

A For the 2020 calendar year, or tax year beginning July 1, 2020, and ending June 30, 20 21

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization Smith-Kingsmore Syndrome Foundation 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, USA, 45011	D Employer identification number 84-2913037 E Telephone number 513 755-1705 F Group Exemption Number ▶
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G Accounting Method: Cash Accrual Other (specify) ▶ _____

I Website: ▶ <https://smithkingsmore.org>

H Check if the organization is not required to attach Schedule B (Form 990, 990-EZ, or 990-PF).

J Tax-exempt status (check only one) - 501(c)(3) 501(c) () ◀ (insert no.) 4947(a)(1) or 527

K Form of organization: Corporation Trust Association Other _____

L Add lines 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total assets (Part II, column (B)) are \$500,000 or more, file Form 990 instead of Form 990-EZ ▶ \$ **102,521**

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (see the instructions for Part I)

Check if the organization used Schedule O to respond to any question in this Part I

Revenue	1 Contributions, gifts, grants, and similar amounts received	1	102,521
	2 Program service revenue including government fees and contracts	2	
	3 Membership dues and assessments	3	
	4 Investment income	4	
	5a Gross amount from sale of assets other than inventory 5a		
	b Less: cost or other basis and sales expenses 5b		
	c Gain or (loss) from sale of assets other than inventory (subtract line 5b from line 5a) 5c	5c	
	6 Gaming and fundraising events:		
	a Gross income from gaming (attach Schedule G if greater than \$15,000) 6a	6a	
b Gross income from fundraising events (not including \$ _____ of contributions from fundraising events reported on line 1) (attach Schedule G if the sum of such gross income and contributions exceeds \$15,000) 6b	6b		
c Less: direct expenses from gaming and fundraising events 6c	6c		
d Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c) 6d	6d		
7a Gross sales of inventory, less returns and allowances 7a	7a		
b Less: cost of goods sold 7b	7b		
c Gross profit or (loss) from sales of inventory (subtract line 7b from line 7a) 7c	7c		
8 Other revenue (describe in Schedule O) 8	8		
9 Total revenue. Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8 ▶ 9	9	102,521	
Expenses	10 Grants and similar amounts paid (list in Schedule O) 10	10	88,852
	11 Benefits paid to or for members 11	11	
	12 Salaries, other compensation, and employee benefits 12	12	
	13 Professional fees and other payments to independent contractors 13	13	
	14 Occupancy, rent, utilities, and maintenance 14	14	
	15 Printing, publications, postage, and shipping 15	15	
	16 Other expenses (describe in Schedule O) 16	16	4,162
17 Total expenses. Add lines 10 through 16 ▶ 17	17	93,014	
Net Assets	18 Excess or (deficit) for the year (subtract line 17 from line 9) 18	18	9,506
	19 Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return) 19	19	15,094
	20 Other changes in net assets or fund balances (explain in Schedule O) 20	20	
21 Net assets or fund balances at end of year. Combine lines 18 through 20 ▶ 21	21	24,600	

Part II Balance Sheets (see the instructions for Part II)

Check if the organization used Schedule O to respond to any question in this Part II

	(A) Beginning of year	(B) End of year
22 Cash, savings, and investments	14,840	23,989
23 Land and buildings		23
24 Other assets (describe in Schedule O)	468	826
25 Total assets	15,308	24,815
26 Total liabilities (describe in Schedule O)	214	214
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	15,094	24,600

Part III Statement of Program Service Accomplishments (see the instructions for Part III)

Check if the organization used Schedule O to respond to any question in this Part III

Expenses
(Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)

What is the organization's primary exempt purpose? Charitable, support of scientific research and awareness.

Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. In a clear and concise manner, describe the services provided, the number of persons benefited, and other relevant information for each program title.

28 Fund research of Smith-Kingsmore syndrome by providing grants to researchers and research institutions. Awarded grants to University of Florida Foundation to support the work of Dr. Andrew Liu at the UF College of Medicine. (Grants \$ 88,852) If this amount includes foreign grants, check here <input type="checkbox"/>	28a	0
29 Increase awareness of Smith-Kingsmore syndrome. Accomplishments include social media campaigns to launch the first Awareness Day and for Rare Disease Day, engaging medical experts & connecting them with families, producing live expert interviews, and collaborating with other rare disease advocacy organizations. (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	29a	242
30 (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	30a	
31 Other program services (describe in Schedule O) (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	31a	
32 Total program service expenses (add lines 28a through 31a)	32	242

Part IV List of Officers, Directors, Trustees, and Key Employees (list each one even if not compensated—see the instructions for Part IV)

Check if the organization used Schedule O to respond to any question in this Part IV

(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
Kristen Groseclose President	20	0		
Sarah Lepore Vice President, Chair, Medical & Scientific Advisory	10	0		
Jessica Walsh Secretary	3	0		
Mike Groseclose Treasurer, Secretary	15	0		
Nazira Kelly Vice Chair, Medical & Scientific Advisory	5	0		
Cassandra Briggs Director	3	0		
Dan Lepore Director	3	0		
Eric Kelly Director	5	0		
Matt Walsh Director	3	0		
Howard Zhou Director	3	0		

Part V Other Information (Note the Schedule A and personal benefit contract statement requirements in the instructions for Part V.) Check if the organization used Schedule O to respond to any question in this Part V [X]

33 Did the organization engage in any significant activity not previously reported to the IRS? If "Yes," provide a detailed description of each activity in Schedule O
34 Were any significant changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the amended documents if they reflect a change to the organization's name. Otherwise, explain the change on Schedule O. See instructions
35a Did the organization have unrelated business gross income of \$1,000 or more during the year from business activities (such as those reported on lines 2, 6a, and 7a, among others)?
35b If "Yes" to line 35a, has the organization filed a Form 990-T for the year? If "No," provide an explanation in Schedule O
35c Was the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization subject to section 6033(e) notice, reporting, and proxy tax requirements during the year? If "Yes," complete Schedule C, Part III
36 Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N
37a Enter amount of political expenditures, direct or indirect, as described in the instructions
37b Did the organization file Form 1120-POL for this year?
38a Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee; or were any such loans made in a prior year and still outstanding at the end of the tax year covered by this return?
38b If "Yes," complete Schedule L, Part II, and enter the total amount involved
39 Section 501(c)(7) organizations. Enter:
39a Initiation fees and capital contributions included on line 9
39b Gross receipts, included on line 9, for public use of club facilities
40a Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under:
40b Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year, or did it engage in an excess benefit transaction in a prior year that has not been reported on any of its prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I
40c Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958
40d Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax on line 40c reimbursed by the organization
40e All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T
41 List the states with which a copy of this return is filed
42a The organization's books are in care of
42b 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)?
42c At any time during the calendar year, did the organization maintain an office outside the United States?
43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041—Check here and enter the amount of tax-exempt interest received or accrued during the tax year
44a Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ
44b Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ
44c Did the organization receive any payments for indoor tanning services during the year?
44d If "Yes" to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O
45a Did the organization have a controlled entity within the meaning of section 512(b)(13)?
45b Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," Form 990 and Schedule R may need to be completed instead of Form 990-EZ. See instructions

46 Did the organization engage, directly or indirectly, in political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I

	Yes	No
46		✓

Part VI Section 501(c)(3) Organizations Only

All section 501(c)(3) organizations must answer questions 47–49b and 52, and complete the tables for lines 50 and 51.

Check if the organization used Schedule O to respond to any question in this Part VI

47 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

	Yes	No
47		✓

48 Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E

	Yes	No
48		✓

49a Did the organization make any transfers to an exempt non-charitable related organization?

	Yes	No
49a		✓

b If "Yes," was the related organization a section 527 organization?

	Yes	No
49b		

50 Complete this table for the organization's five highest compensated employees (other than officers, directors, trustees, and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and title of each employee	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
None				

f Total number of other employees paid over \$100,000 **0**

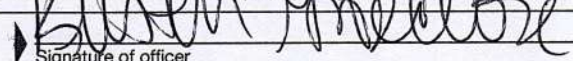
51 Complete this table for the organization's five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and business address of each independent contractor	(b) Type of service	(c) Compensation
None		

d Total number of other independent contractors each receiving over \$100,000 **0**

52 Did the organization complete Schedule A? **Note:** All section 501(c)(3) organizations must attach a completed Schedule A **Yes** **No**

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 Date 9/19/2021

 Signature of officer
Kristen Groseclose, President, Smith-Kingsmore Syndrome Foundation
 Type or print name and title

Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN
	Firm's name ▶	Firm's EIN ▶			
	Firm's address ▶	Phone no.			

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

SCHEDULE A
(Form 990 or 990-EZ)

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 for instructions and the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization

Smith-Kingsmore Syndrome Foundation

Employer identification number

84-2913037

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 or 990-EZ).)
- 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)						
Total						

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")				\$16,863	\$102,521	\$119,384
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	\$119,384
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4						\$119,384

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7 Amounts from line 4				\$16,863	\$102,521	\$119,384
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, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						\$119,384
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input checked="" type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2020 (line 6, column (f), divided by line 11, column (f))	14	%
15 Public support percentage from 2019 Schedule A, Part II, line 14	15	%
16a 33 1/3% support test—2020. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
b 33 1/3% support test—2019. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
17a 10%-facts-and-circumstances test—2020. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
b 10%-facts-and-circumstances test—2019. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization ▶ <input type="checkbox"/>		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ▶ <input type="checkbox"/>		

**SCHEDULE O
(Form 990 or 990-EZ)**

Department of the Treasury
Internal Revenue Service

Name of the organization

Smith-Kingsmore Syndrome Foundation

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 990-EZ.

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

OMB No. 1545-0047

2020

**Open to Public
Inspection**

Employer identification number

84-2913037

Form 990-EZ, Part 1, Line 10 Grants Paid:

Grants awarded to University of Florida Foundation, supporting the work of Dr. Andrew Liu at the UF College of Medicine

8/25/20 UF Foundation Grant \$25,000

9/11/20 UF Foundation Grant \$33,852

6/14/21 UF Foundation Grant \$30,000

Total \$88,852

Form 990-EZ, Part 1, Line 16 Other Expenses:

Credit Card Processing, Bank Fees \$2,186

Directors & Officers Insurance \$708

Frontstream Panorama Digital Fundraising Platform \$600 (fee paid by SKSF Board donation)

Foundation Directory Online Grant Search Platform \$425 (fee paid by SKSF Board donation)

National Organization for Rare Disorders Annual Dues \$150 (collaboration with other rare disease advocacy organizations)

National Organization for Rare Disorders Conference Fee \$93 (collaboration with other rare disease advocacy organizations)

Total \$4,162

Form 990-EZ, Part II, Line 24 Other Assets:

Accounts Receivable (Individual Contributions) \$826

Form 990-EZ, Part II, Line 26 Total Liabilities:

Accounts Payable (Insurance) \$214