	0		Poturn	of Organization Ex	vomnt	Erom I	ncol	ma Tay	,	OMB No. 1545-0047	
Form	95	<i>)</i> U	Return of Organization Exempt From Income Tax								
			Under section 501(c),	dations)	2021						
Depart	ment of	the Treasury	Do not en	ter social security numbers o	on this form	n as it may	be mad	de public.		Open to Public	
		ue Service	Go to v	vww.irs.gov/Form990 for inst	ructions a	nd the lates	t inforr	nation.		Inspection	
<u>A</u> F	For the 2021 calendar year, or tax year beginning 07-01, 2021, and ending 06-									-30 , <b>20</b> 22	
<b>В</b> с	heck if a	pplicable:	C Name of organizationSm	ith-Kingsmore Syndro	ome Four	ndation			D Emplo	over identification number	
Δ Α	ddress c	change	Doing business as							84-2913037	
∐ N	ame cha	ange	Number and street (or P.	O. box if mail is not delivered to street ac	ddress)		Room/s	uite	E Teleph	none number	
L In	itial retu	rn	5903 Franklin	Trl						(513) 755-1705	
E Fi	nal retu	rn/terminated	City or town, state or pro	vince, country, and ZIP or foreign postal	code				G Gross	receipts	
	mended	return	Liberty Twp, C	DH 45011					\$	655,714	
L A	oplicatio	n pending	F Name and address of pr	incipal officer: Kristen Grose	close			H(a) Is this a	group return f	or subordinates? Yes X No	
			Same as C abov					H(b) Are all	subordinate	es included? Yes No	
			501(c)(3) 501(c) (	) < (insert no.) 4947(a)(1) o	or 5	27				t. See instructions	
	ebsite:		ps://smithkingsmo	<u> </u>				H(c) Group			
Par		rganization: X		ociation 🔄 Other 🏲	L	Year of formati	on: 20	19 M	State of lega	al domicile: OH	
Fai	-	•		ion or most significant activities				a : . 1 =		<u>, ,  </u>	
	1	-	-	ion or most significant activities			n of	Smith-K	ingsmo	ore syndrome by	
Ice		providing	g grants to resea	rchers and research	institi	itions.					
nan											
Governance	2	Chock this be		n discontinued its operations or	disposed o	of more than	25% of	ite not acco	ote		
ê	3			•	•				1 1	0	
Š	4			rs of the governing body (Part V						8	
Activities &	5			n calendar year 2021 (Part V, lir						0	
tiv	6		of volunteers (estimate if							20	
Ă			,	Part VIII, column (C), line 12					. 7a	0	
				from Form 990-T, Part I, line 11					-	0	
								Prior Year		Current Year	
	8	Contributions	and grants (Part VIII, line	1h)			. —		2,521	655,233	
ne	9			e 2g)					,	0	
Revenue	10	-		A), lines 3, 4, and 7d)						0	
Re	11	Other revenu	e (Part VIII, column (A), lii	nes 5, 6d, 8c, 9c, 10c, and 11e)						481	
	12	Total revenue	e - add lines 8 through 11 (	(must equal Part VIII, column (A	A), line 12)			102	2,521	655,714	
	13	Grants and s	imilar amounts paid (Part	IX, column (A), lines 1-3)				88	3,852	58,853	
	14	Benefits paid	to or for members (Part I)	X, column (A), line 4) • • • •						0	
S	15	Salaries, othe	er compensation, employe	e benefits (Part IX, column (A),	lines 5-10)	)				0	
Expenses	16a	Professional	fundraising fees (Part IX,	column (A), line 11e)						600	
per	b	Total fundrais	sing expenses (Part IX, co	lumn (D), line 25) 🕨		16,598					
ŭ	17	Other expense	ses (Part IX, column (A), li	nes 11a-11d, 11f-24e) •••			· 🔔	4	1,162	24,740	
	18	Total expense	es. Add lines 13-17 (must	equal Part IX, column (A), line	25)		· 🖵	93	3,014	84,193	
	19	Revenue less	s expenses. Subtract line	18 from line 12			•	9	9,507	571,521	
or Ices								inning of Curi	rent Year	End of Year	
Net Assets or Fund Balances	20		,					24	4,815	596,122	
at As nd E	21		<b>(</b>						214	0	
	22			line 21 from line 20			•	24	4,601	596,122	
Par		Signatu			and atatamant	a and to the her		audadaa and k	aliaf it is		
				urn, including accompanying schedules a ficer) is based on all information of which				iowiedge and L	beller, it is		
		<b>N</b>									
Sigr			ten Groseclose						Dat	<u> </u>	
Here									Dui	0	
ileit	-		ten Groseclose, P print name and title	resident							
		Print/Type pre		Preparer's signature		Date				PTIN	
Paic							22	Check	· · ·		
	arer	Firm's name	Mullins	John Mullins		11-09-20			nployed	P01429307	
	Only			consin Avenue				Firm's EIN			
230	<b>_</b> ]			MD 20814				Phone no.	202-5	770-6371	
Mav t	he IRS	Giscuss this		nown above? See instructions						XYes No	
			on Act Notice, see the se							Form <b>990</b> (2021)	

Form	n 990 (2021) Smith-Kingsmore Syndrome Foundation	84-2913037	Page <b>2</b>
	Int 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 researche	rs 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?		
	If "Yes," describe these new services on Schedule O.	tes <u>x</u>	JNO
3	Did the organization cease conducting, or make significant changes in how it conducts, any program		
3	services?		No
	If "Yes," describe these changes on Schedule O.		JNO
4	Describe the organization's program service accomplishments for each of its three largest program services, as mea	isured by	
•	expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations	•	
	the total expenses, and revenue, if any, for each program service reported.	,	
4a	(Code:) (Expenses \$66,703 including grants of \$58,853 ) (Reven		)
	This year, Smith-Kingsmore Syndrome Foundation (SKSF) has funded a 3rd yea		
	syndrome (SKS) foundational research at the University of Florida in Dr. L		
	bringing its total investment in this work to \$178,485. This initial 3-yea		
	spark larger research funding. SKSF collaborated with its Medical & Scient		MSA) to
	produce the SKS Report for NORD's Rare Disease Database and patient inform		20
	providing critical information for both medical professionals and family m community. In addition, SKS increased engagement through campaigns for Awa		
	Disease Day, connecting medical experts with families, and collaborating w		
	advocacy organizations.	<u>ren otner rare (</u>	arsease
4b	(Code:) (Expenses \$ including grants of \$ ) (Reven	ue \$	)
4c	(Code:) (Expenses \$ including grants of \$ ) (Reven	ue \$	)
4d	Other program services (Describe on Schedule O.)		
<u> </u>	(Expenses \$ including grants of \$ ) (Revenue \$	)	
<u>4e</u>	Total program service expenses <b>66,703</b>		000 (2024)

Form 990 (2	2021
Part IV	(

1)	Smith-Kingsmore	Syndrome	Foundation
Checklist of	<b>Required Schedul</b>	es	

Т

1

			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		x
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II	4		v
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues,	-		<u>x</u>
5	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			
Ũ	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? If "Yes,"			
	complete Schedule D, Part III	8		х
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		х
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? If "Yes,"			
	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		X
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets	44.4		
	reported in Part X, line 16? If "Yes," complete Schedule D, Part IX	11d		<u>x</u>
e f	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e		x
1	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	11f		v
12a				x
12a	Schedule D, Parts XI and XII	12a		x
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		x
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>	13		x
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		x
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking,			
	fundraising, business, investment, and program service activities outside the United States, or aggregate			
	foreign investments valued at \$100,000 or more? 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			
40	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?			
<b>20</b> -	If "Yes," complete Schedule G, Part III	19		X
20 a		20a 20b		x
b 21	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or	200		
21	domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	x	
			~	

	990 (2021) Smith-Kingsmore Syndrome Foundation	84-29130	37	Р	age <b>4</b>
Pa	rt IV Checklist of Required Schedules (continued)				
		1		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		x
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the				
	organization's current and former officers, directors, trustees, key employees, and highest compensated				
	employees? 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		х
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		24b		L
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		L
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		24d		<b> </b>
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		х
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		х
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		х
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		х
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L,				
	Part IV instructions, for applicable filing thresholds, conditions, and exceptions):				
а	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If				
	"Yes," complete Schedule L, Part IV • • • • • • • • • • • • • • • • • •		28a		х
b	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV		28b		х
С	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If				
	"Yes," complete Schedule L, Part IV		28c		х
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M		29		х
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified				
	conservation contributions? If "Yes," complete Schedule M		30		х
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I		31		х
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes,"				
	complete Schedule N, Part II		32		х
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations				
	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I		33		х
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III,				
	or IV, and Part V, line 1 • • • • • • • • • • • • • • • • • •		34		х
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		35a		х
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a				
	controlled entity within the meaning of section 512(b)(13)? 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		х
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		х
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	
Par					_
	Check if Schedule O contains a response or note to any line in this Part V	<u></u>			
_		,		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	0			
b	Enter the number of Form W-2G included in line 1a. Enter -0- if not applicable	0			
С	Did the organization comply with backup withholding rules for reportable payments to vendors and		4.4		
	reportable gaming (gambling) winnings to prize winners?		1c	Х	<u> </u>

Form 990 (2021)

	990 (2021) Smith-Kingsmore Syndrome Foundation 84-2913	)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 0			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	x	
	Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.			
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		х
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		х
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		х
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		х
с	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the			
	organization solicit any contributions that were not tax deductible as charitable contributions?	6a		х
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		х
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		х
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		х
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 10b			
11	Section 501(c)(12) organizations. Enter:			
а	Gross income from members or shareholders 11a			
b	Gross income from other sources (Do not net amounts due or paid to other sources			
	against amounts due or received from them.)			
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.			
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			
с	Enter the amount of reserves on hand 13c			
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		х
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b		
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or			
	excess parachute payment(s) during the year?	15		x
	If "Yes," see 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		х
	If "Yes," complete Form 4720, Schedule O.			
17	Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in any			
	activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953?	17		
	If "Yes," complete Form 6069.			

Forr	m 990 (2021) Smith-Kingsmore Syndrome Foundation 84-29130		Р	age <b>6</b>
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			. x
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 <b> 1b</b>			
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	-	А	
•	supervision of officers, directors, or trustees, or key employees to a management company or other person?	3		x
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		x
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5		x
6	Did the organization have members or stockholders?	6		x
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint			
	one or more members of the governing body?	7a		x
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		x
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			
<u> </u>	the organization's mailing address? If "Yes," provide the names and addresses on Schedule O	9		X
Jec	tion B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)			
10a	Did the organization have local chapters, branches, or affiliates?	10a	Yes	No V
	If "Yes," did the organization have written policies and procedures governing the activities of such chapters,	104		x
~	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	x	
b	Describe in 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 in 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		x
15	Did the process for determining compensation of the following persons include a review and approval by			
	independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
a	The organization's CEO, Executive Director, or top management official	15a		x
b	Other officers or key employees of the organization	15b		x
46-	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	460		
b	with a taxable entity during the year?	16a		x
U	participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the			
	organization's exempt status with respect to such arrangements?	16b		
Sec	tion C. Disclosure	100		
<u></u> 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. Indicate how you made these available. Check all that apply.			
	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	1) Smith-Kingsmore Syndrome Foundation	84-2913037	Page 7
Part VII	Compensation of Officers, Directors, Trustees, Key Employees, Highest C Independent Contractors	ompensated Employe	es, and
	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 t	his 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.

$\mathbf{x}$ Check this box if heither the organization for any rela	leu organiza		inhe	115a	ieu a	any cu	nen	t onicer, unector, o	แนรเยย.	
				(	(C)					
(A)	(B)	Position (do not check more than one						(D)	(E)	(F)
Name and title	Average					han one s both ai		Reportable	Reportable	Estimated amount
	hours			•		/trustee)		compensation	compensation	of other
	per week							from the organization (W-2/	from related organizations W-2/	compensation from the
	(list any hours for	Ind or c	Ins	Office	Key	em Hig	For	1099-MISC/	1099-MISC/	organization and
	related	ividu direc	titutic	icer	/ em	ploy	Former	1099-NEC)	1099-NEC	related organizations
	organizations	al tru tor	onal		Key employee	ee				
	below	Individual trustee or director	Institutional trustee		ee	Ipen				
	dotted line)	÷	ee			Highest compensated employee				
						<u>а</u>				
(1) Eric Kelly	<u>5.0</u> 0									-
Director		х						0	0	0
(2) Matt Walsh	<u>1.00</u>									
Director		х						0	0	0
(3) Cass Briggs	2.00									
Director		х						0	0	0
(4) Dan Lepore	2.00									
Director		х						0	0	0
(5) Nazira Kelly	<u> </u>									
Vice Chair Medical Advisory		х		Х				0	0	0
(6) Sarah Lepore	<u>7 .0</u> 0							o		•
Vice President, Chair Medical Advis	20.00	х		Х				0	0	0
(7) Kristen Groseclose	<u>30.00</u>							o	0	0
President	15 00	х		х				0	0	0
(8) Mike_Groseclose Treasurer and Interim Secretary		x		v				o	0	0
(0)		X		X				0	0	0
<u>(9)</u>										
<u>(10)</u>										
<u>(11)</u>										
(12)										
<u>(13)</u>										
<u>(14)</u>										
										<b>5 000</b> (0001)

# Form 990 (2021)

P	age <b>8</b>

	(B) Average hours per week	(do not check more than one       proge     box, unless person is both an       ours     officer and a director/trustee)       week     from the							(E) Reportal compensa from relat	ition ted	(F) Estimated a of othe compens:			
		(list any hours for related organizations below dotted line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former	organization (W-2/ 1099-MISC/ 1099-NEC)	organization 1099-MIS 1099-NE	sc/	orga	from the anization d organiz	
(15)														
(16)														
<u>(17)</u>														
<u>(18)</u>														
<u>(19)</u>														
(20)														
<u>(21)</u>														
(22)				╞──┤										
(23)														
<u>(24)</u>														
(25)														
1b	Subtotal			ш • • <i>·</i>				. <b>.</b>	•					
c d	Total from continuation sheets to Part VII, Sec Total (add lines 1b and 1c)				•••	•••		•	. 0		0			0
2	Total number of individuals (including but not limit reportable compensation from the organization	ed to those li						d mo	-	of				0
3	Did the organization list any <b>former</b> officer, directo		ev emr			r hic	ubest c	omr	nensated				Yes	No
J	employee on line 1a? If "Yes," complete Schedule			-		-			•••••			3		x
4	For any individual listed on line 1a, is the sum of r organization and related organizations greater that													
F	individual		••••	•••	•••	• •	•••	•••				4		x
5	for services rendered to the organization? If "Yes,							-				5		x
	on B. Independent Contractors													
1	Complete this table for your five highest compens compensation from the organization. Report comp										ax year.			
	(A) Name and business addres	s							(B) Description of servic	es		(C) Compens	sation	
2	Total number of independent contractors (includin received more than \$100,000 of compensation from the structure of the struc	-				ted	above	) wh	10					

Form 99			n-Kingsmore	Sync	drome Foundat	ion		84-29130	37 Page 9
Part	VIII	Statement of Rev Check if Schedule O co		se or n	ote to any line in thi	is Part VIII			Г
						(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512–514
	_ 1a	Federated campaigns .		1a					
ts ts	b	Membership dues • • •		1b					
Contributions, Gifts, Grants and Other Similar Amounts	c	Fundraising events		1c					
Am C	d	Related organizations •		1d					
, Gif	e	Government grants (cont		1e					
Sim	f	All other contributions, gil and similar amounts not i	-	1f	655 000				
buti	g	Noncash contributions in			655,233				
d O II	9	lines 1a-1f		1g	\$				
ရှိ ပိ	h	Total. Add lines 1a-1f				655,233			
					Business Code				
e	2a								
с С	b								
Program Service Revenue	c								
am eve	d								
ogr R	е								
<b>P</b>		All other program service I							
	-	Total. Add lines 2a-2f .							
	3	Investment income (includ							
		other similar amounts)							
		Income from investment of		•					
	5	Royalties							
	6a	Gross rents	(i) Re	ai	(ii) Personal				
		Less: rental expenses							
		Rental income or (loss)	60 60						
		Net rental income or (loss)			· · · · · · •				
		Gross amount from	(i) Secur		(ii) Other				
		sales of assets							
		other than inventory	7a						
	b	Less: cost or other basis							
Jue		and sales expenses							
ver		Gain or (loss)							
Other Revenue		Net gain or (loss) • • • •		· · <u>· ·</u>	· · · · · · •				
the	8a	Gross income from fundra	aising						
õ		events (not including \$		_					
		of contributions reported o							
	h	1c). See Part IV, line 18 Less: direct expenses							
		Net income or (loss) from			′ <u> </u>				
		Gross income from gaming	-						
		activities, See Part IV, line	-	. 9a					
	b	Less: direct expenses							
		Net income or (loss) from			•••••				
	10a	Gross sales of inventory, le	ess						
		returns and allowances .		. 10a	a				
	b	Less: cost of goods sold		. 10k	þ				
	c	Net income or (loss) from	sales of invento	ry					
					Business Code				
a	11a	Other			900099	481	481		
and	b								
eve	С								ļ
Miscellanous Revenue		All other revenue							
-		Total. Add lines 11a-11d				481			
	12	Total revenue See instru	ictions			655 714	481	0	<u>م</u>

#### Smith-Kingsmore Syndrome Foundation Statement of Functional Expenses

Sect	ion 501(c)(3) and 501(c)(4) organizations must complete all co	lumns. All other organiz	ations must complete o	column (A).	
	Check if Schedule O contains a response or note to	any line in this Part IX			
Do n	ot include amounts reported on lines 6b, 7b,	<b>(A)</b> Total expenses	(B) Program service	(C) Management and	<b>(D)</b> Fundraising
8b, 9	b, and 10b of Part VIII.		expenses	general expenses	expenses
1	Grants and other assistance to domestic organizations				
	and domestic governments. See Part IV, line 21	58,853	58,853		
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				
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 10	Other employee benefits				
10 11	Payroll taxes				
	Management				
a h		1 570			1 570
b	Accounting	1,573			1,573
c d					
e e	Professional fundraising services. See Part IV, line 17	600			600
f	Investment management fees	600			600
g	Other. (If line 11g amount exceeds 10% of line 25, column				
y	(A) amount, list line 11g expenses on Schedule O.)	20,950	7,500		13,450
12	Advertising and promotion	20,950	7,500		13,450
13	Office expenses	1,411	350	185	876
14	Information technology	312		213	99
15	Royalties	512		213	
16					<u>_</u>
17	Travel				
18	Payments of travel or entertainment expenses				
	for any federal, state, or local public officials				
19	Conferences, conventions, and meetings				
20					
21	Payments to affiliates				
22	Depreciation, depletion, and amortization				
23	Insurance	494		494	
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	84,193	66,703	892	16,598
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)				

Form 990	(2021)	)	Smith-Kingsmore	Syndrome	Foundatio

Page 11	Page	1	1
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	990 (20		84	4-291	.3037 Page 11
Par	t X	Balance Sheet			
	-	Check if Schedule O contains a response or note to any line in this Part X			
			<b>(A)</b> Beginning of year		<b>(B)</b> End of year
	1	Cash - non-interest-bearing	23,989	1	195,926
	2	Savings and temporary cash investments	- /	2	,
	3	Pledges and grants receivable, net	826	3	400,196
	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	
<i>(</i> 0	7	Notes and loans receivable, net		7	
Assets	8	Inventories for sale or use		8	
Ass	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)	24,815	16	596,122
	17	Accounts payable and accrued expenses	214	17	•
	18	Grants payable		18	
	19	Deferred revenue		19	
	20	Tax-exempt bond liabilities		20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
S	22	Loans and other payables to any current or former officer, director,			
liti		trustee, key employee, creator or founder, substantial contributor, or 35%			
Liabilities		controlled entity or family member of any of these persons		22	
	23	Secured mortgages and notes payable to unrelated third parties		23	
	24	Unsecured notes and loans payable to unrelated third parties		24	
	25	Other liabilities (including federal income tax, payables to related third			
		parties, and other liabilities not included on lines 17-24). Complete Part X			
		of Schedule D		25	
	26	Total liabilities. Add lines 17 through 25	214	26	0
		Organizations that follow FASB ASC 958, check here			
ses		and complete lines 27, 28, 32, and 33.			
anc	27	Net assets without donor restrictions	23,601	27	19,308
Bal	28	Net assets with donor restrictions	1,000	28	576,814
Ιpι		Organizations that do not follow FASB ASC 958, check here			
Fui		and complete lines 29 through 33.			
r	29	Capital stock or trust principal, or current funds		29	
ets	30	Paid-in or capital surplus, or land, building, or equipment fund		30	
Net Assets or Fund Balances	31	Retained earnings, endowment, accumulated income, or other funds		31	
et /	32	Total net assets or fund balances	24,601	32	596,122
	33	Total liabilities and net assets/fund balances	24,815	33	596,122

EEA

Form 990 (2021)

Form		84-291303	7	Pa	age <b>12</b>
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		655,	
2	Total expenses (must equal Part IX, column (A), line 25)	. 2		84,	193
3	Revenue less expenses. Subtract line 2 from line 1	. 3		571,	521
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	. 4		24,	601
5	Net unrealized gains (losses) on investments	. 5			
6	Donated services and use of facilities	. 6			
7	Investment expenses				
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		596,	122
Pa	rt XII Financial Statements and Reporting				
	Check if Schedule O contains a response or note to any line in this Part XII				<u>.                                    </u>
				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				
	Single Audit Act and OMB Circular A-133?		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		
			Earm	000 /	0024

Form 990 (2021)

SCHEDULE	A
(Form 990)	

Name of the organization

# **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

Department of the Treasury Internal Revenue Service

Attach to Form 990 or Form 990-EZ. ► Go to www.irs.gov/Form990 for instructions and the latest information.

<b>t</b>	OMB No. 1545-0047
DORT mpt charitable trust.	2021
	Open to Public
mation.	Inspection

		Kingsmore Syndrome Foun		I erzenizetiene mu		ata thia r	84-291303				
Par		Reason for Public Cha	•	<u> </u>			bart.) See Instructi	ons.			
The o	gar	nization is not a private foundation be	ecause it is: (For lir	nes 1 through 12, check	only one b	ox.)					
1	Ц	A church, convention of churches, o	or association of ch	urches described in sec	tion 170(b	)(1)(A)(i).					
2	Ц	A school described in <b>section 170(b)(1)(A)(ii).</b> (Attach Schedule E (Form 990).)									
3	Ц	A hospital or a cooperative hospital	service organization	on described in section '	170(b)(1)(A	A)(iii).					
4	Ш	A medical research organization op	erated in conjunction	on with a hospital descrit	ped in sect	ion 170(b)	(1)(A)(iii). Enter the				
	_	hospital's name, city, and state:									
5	Ш	An organization operated for the be	-	r university owned or ope	erated by a	governme	ental unit described in				
		section 170(b)(1)(A)(iv). (Complete	,								
6	Ц	A federal, state, or local governmen	0								
7	Х	An organization that normally received			governmen	tal unit or f	rom the general public				
_		described in section 170(b)(1)(A)(v		,							
8	Н	A community trust described in <b>sec</b>		,							
9	Ш	An agricultural research organizatio				•		е			
		or university or a non-land-grant co	llege of agriculture	(see instructions). Enter	the name,	city, and s	tate of the college or				
40		university:	(4)	00.4/00/ 51							
10		An organization that normally receive receipts from activities related to its support from gross investment inco	exempt functions, me and unrelated l	subject to certain excep business taxable income	tions; and (less sect	(2) no mor ion 511 tax	e than 33 1/3% of its	SS			
11		acquired by the organization after J An organization organized and oper	,		•	,					
12	Н	An organization organized and ope						ses of			
		one or more publicly supported orga					, , ,				
		the box in lines 12a through 12d that									
а		<b>Type I.</b> A supporting organization	•••			•	-	q			
		the supported organization(s) the				-		0			
		supporting organization. <b>You m</b>									
b		<b>Type II.</b> A supporting organizati	-		vith its sup	ported orga	anization(s), by having				
		control or management of the s	•			-		ed			
		organization(s). You must con	plete Part IV, Sec	tions A and C.							
с		Type III functionally integrate	d. A supporting or	anization operated in co	nnection w	vith, and fu	nctionally integrated wit	:h,			
		its supported organization(s) (s	ee instructions). Yo	ou must complete Part	IV, Sectio	ns A, D, ar	nd E.				
d		Type III non-functionally integ	grated. A supportin	g organization operated	in connect	ion with its	supported organization	n(s)			
		that is not functionally integrate	d. The organizatior	n generally must satisfy a	a distributio	on requiren	nent and an attentivene	ess			
		requirement (see instructions).	You must comple	te Part IV, Sections A a	nd D, and	Part V.					
е		Check this box if the organization	on received a writte	en determination from the	e IRS that	it is a Type	I, Type II, Type III				
		functionally integrated, or Type	•	integrated supporting or	ganization	•					
f	E	nter the number of supported organ	izations								
g	Ρ	rovide the following information abo	ut the supported or	ganization(s).	1						
	(i) N	ame of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the o listed in you docum	ir governing	(v) Amount of monetary support (see instructions)	other	Amount of support (see structions)		
					Yes	No					
					100						
(A)											
(B)											
(C)											
(D)											
(E)											
Total											

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

	le A (Form 990) 2021 Smith-Kings	smore Syndr	ome Foundat	tion		84-291303	
Part							
	(Complete only if you checked the second	ne box on lin	e 5, 7, or 8 of	Part I or if th	e organizatio	n failed to qu	alify under
	Part III. If the organization fails to	o qualify und	er the tests li	sted below, p	lease comple	ete Part III.)	
Secti	on A. Public Support						
Calen	dar year (or fiscal year beginning in) 🕨	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")			16,863	102,521	655,233	774,617
2	Tax revenues levied for the			10,803	102,521	055,235	//4,01/
-	organization's benefit and either paid to						
	-						
2	•						
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	774,617
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)						148
6	Public support. Subtract line 5 from line 4 .						774,469
Secti	on B. Total Support		I	L			,
	dar year (or fiscal year beginning in) 🕨	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
7	Amounts from line 4			16,863	102,521	655,233	774,617
8	Gross income from interest, dividends,			20,003		0007200	
-	payments received on securities loans,						
	rents, royalties, and income from						
	similar sources						
9	Net income from unrelated business						
5	activities, whether or not the business						
	is regularly carried on						
10	Other income. Do not include gain or						
10							
	loss from the sale of capital assets						
	(Explain in Part VI.)					481	481
11	Total support. Add lines 7 through 10						775,098
12	Gross receipts from related activities, etc.	•	,			12	
13	First 5 years. If the Form 990 is for the o	0				· · · · ·	· · · · _
	organization, check this box and stop he						🕨 🗴
	on C. Computation of Public Suppo		-			i	
14	Public support percentage for 2021 (line 6		•			14	%
15	Public support percentage from 2020 Sch					15	%
16a	33 1/3% support test - 2021. If the organ						
	box and stop here. The organization qua		• • •	-			_
b	33 1/3% support test - 2020. If the organ	nization did no	t check a box o	on line 13 or 16	a, and line 15	is 33 1/3% or r	nore, check
	this box and stop here. The organization	qualifies as a	publicly suppo	rted organizati	on		🕨 🗌
17a	10%-facts-and-circumstances test - 20	21. If the orga	nization did no	t check a box o	on line 13, 16a	, or 16b, and lir	ne 14 is
	10% or more, and if the organization mee	ts the facts-ar	nd-circumstanc	es test, check	this box and <b>s</b> t	top here. Expla	ain in
	Part VI how the organization meets the fa					• •	
	organization			-	-		🕨 🗖
b	10%-facts-and-circumstances test - 20						Ind line
	15 is 10% or more, and if the organization	•					
	in Part VI how the organization meets the					-	-
	organization				•		
18	<b>Private foundation.</b> If the organization di						
	instructions						

-	e A (Form 990) 2021 Smith-Kings	more Syndr	ome Foundat	tion		84-291303	37 Page 3
Part							
	(Complete only if you checked th	e box on line	e 10 of Part I	or if the orga	nization failed	l to qualify u	nder Part II.
	If the organization fails to qualify	under the te	sts listed bel	ow, please co	omplete Part I	l.)	
Secti	on A. Public Support						
Calen	dar year (or fiscal year beginning in)►	<b>(a)</b> 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1	Gifts, grants, contributions, and membership fees						
	received. (Do not include any "unusual grants.") •						
2	Gross receipts from admissions, merchandise						
	sold or services performed, or facilities furnished in any activity that is related to the						
	organization's tax-exempt purpose						
3	Gross receipts from activities that are not an						
	unrelated trade or business under section 513						
4	Tax revenues levied for the						
	organization's benefit and either paid to						
	or expended on its behalf						
5	The value of services or facilities						
	furnished by a governmental unit to the						
	organization without charge						
6	Total. Add lines 1 through 5						
7a	Amounts included on lines 1, 2, and 3						
	received from disqualified persons .						
b	Amounts included on lines 2 and 3						
	received from other than disqualified						
	persons that exceed the greater of \$5,000						
	or 1% of the amount on line 13 for the year						
-	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6.)						
Secti	on B. Total Support						
	dar year (or fiscal year beginning in)►	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
9	Amounts from line 6	( <b>a</b> ) 2017	(b) 2010	(C) 2019	(u) 2020	(e) 2021	
5 10a	Gross income from interest, dividends,						
Iva	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	ifth tax year as	a section 501	(c)(3)
	organization, check this box and stop her						► 🗌
Secti	on C. Computation of Public Suppo	rt Percentag	e				
15	Public support percentage for 2021 (line 8	8, column (f), d	livided by line	13, column (f))		15	%
16	Public support percentage from 2020 Sch					16	%
Secti	on D. Computation of Investment In	come Perce	ntage				
17	Investment income percentage for 2021 (I			•	( ) )	17	%
18	Investment income percentage from 2020					18	%
19a	33 1/3% support tests - 2021. If the orga						
	17 is not more than 33 1/3%, check this b	-	-	-			
b	33 1/3% support tests - 2020. If the organization						۱
	line 18 is not more than 33 1/3%, check this box						·.··▶ Ц
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 instru	ctions 🕨 📋

### 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

- 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 person who directly or indirectly controls, either alone or together with persons described in lines 11b and			
u	11c below, the governing body of a supported organization?	11a		
	A family member of a person described in line 11a above?	11b		
С	A 35% controlled entity of a person described in 11a or 11b above? If "Yes" to line 11a, 11b, or 11c,			
<del></del>	provide detail in Part VI.	11c		
Section	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 operated, supervised, or controlled the supporting organization of the supported organization of the support of t			
	,			
	<b>VI</b> how providing such benefit carried out the purposes of the supported organization(s) that operated,	~		
<u> </u>	supervised, or controlled the supporting organization.	2		
Section	on C. Type II Supporting Organizations			
			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors			
	or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control			
	or management of the supporting organization was vested in the same persons that controlled or managed			
	the supported organization(s).	1		
Section	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			
		1		
2	organization's governing documents in effect on the date of notification, to the extent not previously provided?	<u> </u>		
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		
Section	on E. Type III Functionally Integrated Supporting Organizations			
1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (se	e insi	tructi	ons).
а	The organization satisfied the Activities Test. Complete line 2 below.			,
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 <b>Part VI</b> how you supported a government entity (see instruction).	<b>m n 1</b>		
		115).	Yes	No
2	Activities Test. <b>Answer lines 2a and 2b below.</b>		Tes	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 <b>Part VI</b> 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. <i>Answer lines 3a and 3b below.</i>			
	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or			
а		20		
L	trustees of each of the supported organizations? <i>If "Yes" or "No," provide details in <b>Part VI</b>.</i>	3a		
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	<b>0</b> L		
	of its supported organizations? If "Yes," describe in <b>Part VI</b> the role played by the organization in this regard.	3b		
EEA	Schedul	e A (Fe	orm 99	0) 2021

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 Schedule A (Form 990) 2021
 Smith-Kingsmore Syndrome Foundation

 Part IV
 Supporting Organizations (continued)

Part				
1	$\Box$ 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 <b>Part VI</b> ). See
	instructions. All other Type III non-functionally integrated supporting organ	nizati	ons 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 <b>Part VI</b> ):			
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	Check here if the current year is the organization's first as a non-functional	ally i	ntegrated Type III suppo	rting organization
	(see instructions).	5		

Smith-Kingsmore Syndrome Foundation

EEA

Schedule A (Form 990) 2021

Schedule A (Form 990) 2021

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	e A (Form 990) 2021 Smith-Kingsmore Syndrome	Foundation	84-2	2913	037 Page 7			
Part	V Type III Non-Functionally Integrated 509(a)	<ol><li>Supporting Organ</li></ol>	izations (continue	ed)				
Section D - Distributions Current								
1	Amounts paid to supported organizations to accomplish e			1				
2	Amounts paid to perform activity that directly furthers exer	ted						
	organizations, in excess of income from activity			2				
3	Administrative expenses paid to accomplish exempt purp	oses of supported orgar	izations	3				
4	Amounts paid to acquire exempt-use assets			4				
	Qualified set-aside amounts (prior IRS approval required)		: <b>VI</b> )	5				
6	Other distributions (describe in Part VI). See instructions.			6				
	Total annual distributions. Add lines 1 through 6.			7				
8	Distributions to attentive supported organizations to which	h the organization is resp	oonsive					
	(provide details in <b>Part VI</b> ). See instructions.			8				
9	Distributable amount for 2021 from Section C, line 6			9				
10	Line 8 amount divided by line 9 amount	1	(11)	10	( <b>**</b> *)			
Secti	on E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributio Pre-2021	ns	(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 - <i>explain in Part VI</i> ). See							
	instructions.							
3	Excess distributions carryover, if any, to 2021							
<u>a</u>	From 2016							
b	From 2017							
<u> </u>	From 2018							
d	From 2019							
e	From 2020							
f	Total of lines 3a through 3e							
	Applied to underdistributions of prior years							
-	Applied to 2021 distributable amount							
<u>     i</u>	Carryover from 2016 not applied (see instructions)							
	Remainder. Subtract lines 3g, 3h, and 3i from line 3f. Distributions for 2021 from							
4	Section D, line 7: \$							
	Applied to underdistributions of prior years							
<u>a</u> b	•••							
C	Remainder. Subtract lines 4a and 4b from line 4.							
5	Remaining underdistributions for years prior to 2021, if							
Ŭ	any. Subtract lines 3g and 4a from line 2. For result							
	greater than zero, <i>explain in Part VI</i> . See instructions.							
6	Remaining underdistributions for 2021. Subtract lines 3h							
Ŭ	and 4b from line 1. For result greater than zero, <i>explain in</i>							
	Part VI. See instructions.							
7	Excess distributions carryover to 2022. Add lines 3j							
-	and 4c.							
8	Breakdown of line 7:							
a	Excess from 2017							
b	Excess from 2018							
C	Excess from 2019							
d	Excess from 2020							
е	Excess from 2021							
EEA					Schedule A (Form 990) 2021			

III, 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.)

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.								OMB No. 1545-0047		
								2021		
Department of the Treasury Attach to Form 990.							L L	Open to Public Inspection		
Internal Revenue Service Go to www.irs.gov/Form990 for the latest information.								ion number		
Smith-Kingsmore Syndrome Foundation										
Part I General	Syndrome Found Information on	ation Grants and Assi	stance				84-2913037			
				istance, the grantees' e	eliaibility for the grants o	r assistance. and				
	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?									
	<ul> <li>2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.</li> </ul>									
Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990,										
			-		ed if additional space	-				
1 (a) Name and addres	s of organization	(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										
Gainesville FL 3	2604	59-0974739	501(c)(3)	58,852				Research		
(2)										
							_			
(3)										
(4)										
(2)										
(5)										
(6)										
(0)										
(7)										
(*)										
(8)										
(9)										
(10)										
							· · · · · · • _			
3 Enter total number of other organizations listed in the line 1 table										

Schedule I (Form 990) (2021) 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	<b>(c)</b> Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance	
1							

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

2

3

4

5

6

7

Part IV

Page **2** 

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# 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 \$20,950