

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2020

Open to Public Inspection

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundation) Do not enter social security numbers on this form as it may be made public.

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

Form 990 Department of the Treasury Internal Revenue Service

A For the 2020 calendar year, or tax year beginning 01-01-2020, and ending 12-31-2020

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

C Name of organization: COALITION FOR USHER SYNDROME RESEARCH INCORPORATED. Doing business as: . . . . . Number and street (or P.O. box if mail is not delivered to street address) Room/suite: 63 GREAT ROAD SUITE 207. City or town, state or province, country, and ZIP or foreign postal code: WESTFORD, MA 01886

D Employer identification number: 26-4560897. E Telephone number: (978) 637-2625. G Gross receipts \$ 236,754

F Name and address of principal officer: LANYA MCKITTRICK, 17837 1ST AVE SO PMB 2, NORMANDY PARK, WA 98148

H(a) Is this a group return for subordinates? No. H(b) Are all subordinates included? No. H(c) Group exemption number

I Tax-exempt status: 501(c)(3)

J Website: WWW.USHER-SYNDROME.ORG

K Form of organization: Corporation

L Year of formation: 2009. M State of legal domicile: MA

Part I Summary

Table with 3 main sections: 1. Activities & Governance (mission statement, 2-7a/b); 2. Revenue (8-12); 3. Expenses (13-19). Includes columns for Prior Year, Current Year, and Net Assets or Fund Balances (20-22).

Part II Signature Block

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

Sign Here: Signature of officer LANYA MCKITTRICK, Date 2021-08-17, Title PRESIDENT

Paid Preparer Use Only: Print/Type preparer's name, Preparer's signature, Date 2021-08-23, Check self-employed, Firm's name KESNER GODES & MORRISSEY LLC, Firm's EIN 04-3534389, Firm's address 15 PACELLA PARK DR STE 200 RANDOLPH, MA 02368

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

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



1 Briefly describe the organization's mission:

RAISE AWARENESS AND ACCELERATE RESEARCH FOR THE MOST COMMON CAUSE OF COMBINED DEAFNESS AND BLINDNESS. PROVIDE INFORMATION AND SUPPORT TO INDIVIDUALS AND FAMILIES AFFECTED BY USHER SYNDROME.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?

Yes No

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

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?

Yes No

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

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

4a (Code: ) (Expenses \$ 142,768 including grants of \$ ) (Revenue \$ 28,681 ) RAISE AWARENESS AND ACCELERATE RESEARCH FOR THE MOST COMMON CAUSE OF COMBINED DEAFNESS AND BLINDNESS. PROVIDE INFORMATION AND SUPPORT TO INDIVIDUALS AND FAMILIES AFFECTED BY USHER SYNDROME.

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

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

(Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ ) RAISE AWARENESS AND ACCELERATE RESEARCH FOR THE MOST COMMON CAUSE OF COMBINED DEAFNESS AND BLINDNESS. PROVIDE INFORMATION AND SUPPORT TO INDIVIDUALS AND FAMILIES AFFECTED BY USHER SYNDROME.

4d Other program services (Describe in Schedule O.)

(Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses 142,768

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 1 through 21, with sub-questions 11a-e and 14a-b. Each row has a corresponding 'Yes' and 'No' column for the answer.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 22 through 38 regarding tax-exempt bond issues, excess benefit transactions, and related party transactions.

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and gaming winnings.

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

Main form area containing questions 2a through 16, with sub-questions and corresponding answer boxes (e.g., 2a, 2b, 3a, 3b, etc.).

If "Yes," complete Form 4720, Schedule O.

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 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



Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members... 2 Did any officer, director, trustee... 3 Did the organization delegate control... 4 Did the organization make any significant changes... 5 Did the organization become aware... 6 Did the organization have members... 7a Did the organization have members... 7b Are any governance decisions... 8 Did the organization contemporaneously document... 8a The governing body? 8b Each committee... 9 Is there any officer, director, trustee...

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... 10b If "Yes," did the organization have written policies... 11a Has the organization provided a complete copy... 11b Describe in Schedule O the process... 12a Did the organization have a written conflict... 12b Were officers, directors, or trustees... 12c Did the organization regularly and consistently... 13 Did the organization have a written whistleblower... 14 Did the organization have a written document... 15 Did the process for determining compensation... 15a The organization's CEO... 15b Other officers or key employees... 16a Did the organization invest in, contribute assets... 16b If "Yes," did the organization follow a written policy...

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed MA
18 Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
19 Describe in 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: KRISTA VASI 63 GREAT ROAD STE 207 MAYNARD, MA 01754 (671) 650-8173

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) LANYA MCKITTRICK PRESIDENT	2.00			X			0	0	0	
(2) KARMEN TRZUPEK TREASURER	2.00			X			0	0	0	
(3) KRISTA VASI EXECUTIVE DI	40.00	X					54,688	0	0	
(4) NANCY CORDERMAN DIRECTOR	2.00	X					0	0	0	
(5) KELLEY STIDD DIRECTOR	2.00	X					0	0	0	
(6) MARGARET KENNA MD MPH DIRECTOR	2.00	X					0	0	0	
(7) WILLIAM KIMBERLING PHD DIRECTOR	2.00	X					0	0	0	
(8) DANAY TREST DIRECTOR	2.00	X					0	0	0	
(9) DAVID ALEXANDER DIRECTOR	2.00	X					0	0	0	
(10) KATHLEEN THOMPSON PHD DIRECTOR	2.00	X					0	0	0	
(11) MONTE WESTERFIELD PHD DIRECTOR	2.00	X					0	0	0	



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

Table with 6 main columns: (A) Name and title, (B) Average hours per week, (C) Position (Individual trustee or director, Institutional Trustee, Officer, Key employee, Highest compensated employee, Former), (D) Reportable compensation from the organization (W-2/1099-MISC), (E) Reportable compensation from related organizations (W-2/1099-MISC), (F) Estimated amount of other compensation from the organization and related organizations.

1b Sub-Total
c Total from continuation sheets to Part VII, Section A
d Total (add lines 1b and 1c) 54,688

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

Table with 3 columns: Question, Yes, No. Contains questions 3, 4, and 5 regarding compensation reporting.

Section B. Independent Contractors

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

Table with 3 columns: (A) Name and business address, (B) Description of services, (C) Compensation

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



Part VIII Statement of Revenue

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

Main table with columns (A) Total revenue, (B) Related or exempt function revenue, (C) Unrelated business revenue, (D) Revenue excluded from tax under sections 512 - 514. Rows include Contributions, Grants, and Other Similar Amounts; Program Service Revenue; and Other Revenue.

Contributions, Gifts, Grants and Other Similar Amounts

Program Service Revenue

Other Revenue

**Part IX Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).  
 Check if Schedule O contains a response or note to any line in this Part IX

<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>	<b>(A)</b> Total expenses	<b>(B)</b> Program service expenses	<b>(C)</b> Management and general expenses	<b>(D)</b> Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21				
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.				
<b>4</b> Benefits paid to or for members				
<b>5</b> Compensation of current officers, directors, trustees, and key employees				
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
<b>7</b> Other salaries and wages	65,058	46,552	11,053	7,453
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits	7,096	4,968	1,064	1,064
<b>10</b> Payroll taxes	5,721	4,100	994	627
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management				
<b>b</b> Legal				
<b>c</b> Accounting	5,200		5,200	
<b>d</b> Lobbying				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees				
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)				
<b>12</b> Advertising and promotion	250	250		
<b>13</b> Office expenses	1,957	1,957		
<b>14</b> Information technology	7,980	7,980		
<b>15</b> Royalties				
<b>16</b> Occupancy	8,495	8,495		
<b>17</b> Travel	604	604		
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings	18,808	18,808		
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization				
<b>23</b> Insurance	2,574	2,574		
<b>24</b> Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
<b>a</b> CONSULTING	43,619	43,619		
<b>b</b> PAYROLL FEE	2,554	1,831	444	279
<b>c</b> BANK CHARGES	1,733		1,733	
<b>d</b> DUES AND SUBSCRIPTIONS	580	580		
<b>e</b> All other expenses	518	450	68	
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	172,747	142,768	20,556	9,423
<b>26</b> <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash-non-interest-bearing . . . . .	114,867	<b>1</b>	168,583
	<b>2</b> Savings and temporary cash investments	20,796	<b>2</b>	20,799
	<b>3</b> Pledges and grants receivable, net . . . . .		<b>3</b>	
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	
	<b>5</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .		<b>9</b>	
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	<b>10a</b>		
	<b>b</b> Less: accumulated depreciation	<b>10b</b>		<b>10c</b>
	<b>11</b> Investments—publicly traded securities . . . . .		<b>11</b>	
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	
	<b>14</b> Intangible assets . . . . .		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11		<b>15</b>	9,850
<b>16 Total assets:</b> Add lines 1 through 15 (must equal line 33) . . . . .		135,663	<b>16</b>	199,232
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .		<b>17</b>	
	<b>18</b> Grants payable . . . . .		<b>18</b>	
	<b>19</b> Deferred revenue . . . . .		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .		<b>24</b>	
<b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17 - 24). Complete Part X of Schedule D		1,060	<b>25</b>	622
<b>26 Total liabilities.</b> Add lines 17 through 25 . . . . .		1,060	<b>26</b>	622
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	99,103	<b>27</b>	163,110
	<b>28</b> Net assets with donor restrictions	35,500	<b>28</b>	35,500
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building or equipment fund . . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		<b>31</b>	
	<b>32</b> Total net assets or fund balances	134,603	<b>32</b>	198,610
<b>33</b> Total liabilities and net assets/fund balances	135,663	<b>33</b>	199,232	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	236,754
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	172,747
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	64,007
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	134,603
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain in Schedule O)	<b>9</b>	
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	<b>10</b>	198,610

**Part XII Financial Statements and Reporting**

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

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

**Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

**Form 990, Special Condition Description:**

**Special Condition Description**

**SCHEDULE A**  
**(Form 990 or 990EZ)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

**Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.**  
**▶ Attach to Form 990 or Form 990-EZ.**  
**▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.**

OMB No. 1545-0047

**2020**

**Open to Public Inspection**

**Name of the organization**

COALITION FOR USHER SYNDROME  
RESEARCH INCORPORATED

**Employer identification number**

26-4560897

**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 **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		
<b>Total</b>						

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

Section A. Public Support

Table with 7 columns: (a) 2016, (b) 2017, (c) 2018, (d) 2019, (e) 2020, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished; 4 Total; 5 The portion of total contributions by each person; 6 Public support.

Section B. Total Support

Table with 7 columns: (a) 2016, (b) 2017, (c) 2018, (d) 2019, (e) 2020, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 9 Net income from unrelated business activities; 10 Other income; 11 Total support; 12 Gross receipts from related activities; 13 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Line number, Description. Rows include: 14 Public support percentage for 2020; 15 Public support percentage for 2019; 16a 33 1/3% support test-2020; b 33 1/3% support test-2019; 17a 10%-facts-and-circumstances test-2020; b 10%-facts-and-circumstances test-2019; 18 Private foundation.



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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .	256,038	198,001	199,266	221,168	192,723	1,067,196
<b>2</b> 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	22,664	36,875		58,892	44,028	162,459
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 . . . . .						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge						
<b>6 Total.</b> Add lines 1 through 5	278,702	234,876	199,266	280,060	236,751	1,229,655
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons						
<b>b</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.						
<b>c</b> Add lines 7a and 7b. .						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						1,229,655

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>9</b> Amounts from line 6. . . . .	278,702	234,876	199,266	280,060	236,751	1,229,655
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .		5	7	4	3	19
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
<b>c</b> Add lines 10a and 10b.		5	7	4	3	19
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on.						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . . .	278,702	234,881	199,273	280,064	236,754	1,229,674
<b>14 First 5 years.</b> 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 <b>stop here.</b> . . . . . <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2020 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	100.000 %
<b>16</b> Public support percentage from 2019 Schedule A, Part III, line 15 . . . . .	<b>16</b>	100.000 %

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for <b>2020</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	0 %
<b>18</b> Investment income percentage from <b>2019</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	0 %

**19a 33 1/3% support tests—2020.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . .

**b 33 1/3% support tests—2019.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . .

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

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

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

**Part IV Supporting Organizations** (continued)

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

**Section B. Type I Supporting Organizations**

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

**Section C. Type II Supporting Organizations**

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

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

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

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

**1** Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (**see instructions**):

- a**  The organization satisfied the Activities Test. Complete **line 2** below.
- b**  The organization is the parent of each of its supported organizations. Complete **line 3** below.
- c**  The organization supported a governmental entity. Describe in **Part VI** how you supported a government entity (see instructions)

**2** Activities Test. **Answer lines 2a and 2b below.**

	Yes	No
<b>a</b> Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
<b>2a</b>		
<b>b</b> Did the activities described in line 2a constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
<b>2b</b>		

**3** Parent of Supported Organizations. **Answer lines 3a and 3b below.**

<b>a</b> Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No" provide details in Part VI.</i>		
<b>3a</b>		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		
<b>3b</b>		

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

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

**Section A - Adjusted Net Income**

(A) Prior Year

(B) Current Year  
(optional)

- |   |          |  |  |
|---|----------|--|--|
| <b>1</b> Net short-term capital gain  | <b>1</b> |  |  |
| <b>2</b> Recoveries of prior-year distributions   | <b>2</b> |  |  |
| <b>3</b> Other gross income (see instructions)  | <b>3</b> |  |  |
| <b>4</b> Add lines 1 through 3  | <b>4</b> |  |  |
| <b>5</b> Depreciation and depletion   | <b>5</b> |  |  |
| <b>6</b> 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) | <b>6</b> |  |  |
| <b>7</b> Other expenses (see instructions)  | <b>7</b> |  |  |
| <b>8 Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)  | <b>8</b> |  |  |

**Section B - Minimum Asset Amount**

(A) Prior Year

(B) Current Year  
(optional)

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

**Section C - Distributable Amount**

Current Year

- |  |          |  |
|--|----------|--|
| <b>1</b> Adjusted net income for prior year (from Section A, line 8, Column A)   | <b>1</b> |  |
| <b>2</b> Enter 85% of line 1   | <b>2</b> |  |
| <b>3</b> Minimum asset amount for prior year (from Section B, line 8, Column A)  | <b>3</b> |  |
| <b>4</b> Enter greater of line 2 or line 3   | <b>4</b> |  |
| <b>5</b> Income tax imposed in prior year  | <b>5</b> |  |
| <b>6 Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | <b>6</b> |  |

- 7**  Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)

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

(continued)

Section D - Distributions		Current Year
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>	
<b>4</b> Amounts paid to acquire exempt-use assets	<b>4</b>	
<b>5</b> Qualified set-aside amounts (prior IRS approval required - provide details in <b>Part VI</b> )	<b>5</b>	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions	<b>6</b>	
<b>7 Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions	<b>8</b>	
<b>9</b> Distributable amount for 2020 from Section C, line 6	<b>9</b>	
<b>10</b> Line 8 amount divided by Line 9 amount	<b>10</b>	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
<b>1</b> Distributable amount for 2020 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2020 (reasonable cause required-- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2020:			
<b>a</b> From 2015. . . . .			
<b>b</b> From 2016. . . . .			
<b>c</b> From 2017. . . . .			
<b>d</b> From 2018. . . . .			
<b>e</b> From 2019. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2020 distributable amount			
<b>i</b> Carryover from 2015 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2020 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2020 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2021.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2016. . . . .			
<b>b</b> Excess from 2017. . . . .			
<b>c</b> Excess from 2018. . . . .			
<b>d</b> Excess from 2019. . . . .			
<b>e</b> Excess from 2020. . . . .			

**Part VI Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part 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).

### Facts And Circumstances Test

Return Reference	Explanation

## **Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**



**Schedule B**

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

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

OMB No. 1545-0047

**2020**

Name of the organization COALITION FOR USHER SYNDROME RESEARCH INCORPORATED	<b>Employer identification number</b> 26-4560897
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**Organization type** (check one):

**Filers of:**

**Section:**

Form 990 or 990-EZ

- 501(c)( ) (enter number) organization
- 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation
- 527 political organization

Form 990-PF

- 501(c)(3) exempt private foundation
- 4947(a)(1) nonexempt charitable trust treated as a private foundation
- 501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.  
**Note:** Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

**General Rule**

- For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or other property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

**Special Rules**

- For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33<sup>1</sup>/<sub>3</sub>% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000 or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.
- For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.
- For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year . . . . . ▶ \$ \_\_\_\_\_

**Caution:** An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization  
COALITION FOR USHER SYNDROME  
RESEARCH INCORPORATED

Employer identification number  
26-4560897

**Part I**  
**Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
RESTRICTED		\$ RESTRICTED	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)

Name of organization  
 COALITION FOR USHER SYNDROME  
 RESEARCH INCORPORATED

**Employer identification number**  
 26-4560897

**Part II Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____

Name of organization COALITION FOR USHER SYNDROME RESEARCH INCORPORATED	Employer identification number 26-4560897
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**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once. See instructions.) ► \$ \_\_\_\_\_

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	

## **Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

**Supplemental Financial Statements**

**2020**

**Open to Public Inspection**

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

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

Department of the Treasury  
Internal Revenue Service

**Name of the organization**  
COALITION FOR USHER SYNDROME  
RESEARCH INCORPORATED

**Employer identification number**  
26-4560897

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

	(a) Donor advised funds	(b) Funds and other accounts
<b>1</b> Total number at end of year . . . . .		
<b>2</b> Aggregate value of contributions to (during year)		
<b>3</b> Aggregate value of grants from (during year)		
<b>4</b> Aggregate value at end of year . . . . .		

**5** Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? . . . . .  **Yes**  **No**

**6** Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? . . . . .  **Yes**  **No**

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

**1** Purpose(s) of conservation easements held by the organization (check all that apply).  
 Preservation of land for public use (e.g., recreation or education)     Preservation of an historically important land area  
 Protection of natural habitat     Preservation of a certified historic structure  
 Preservation of open space

**2** Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

	Held at the End of the Year
<b>a</b> Total number of conservation easements . . . . .	<b>2a</b>
<b>b</b> Total acreage restricted by conservation easements . . . . .	<b>2b</b>
<b>c</b> Number of conservation easements on a certified historic structure included in (a) . . . . .	<b>2c</b>
<b>d</b> Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register . . . . .	<b>2d</b>

**3** Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ \_\_\_\_\_

**4** Number of states where property subject to conservation easement is located ▶ \_\_\_\_\_

**5** Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? . . . . .  **Yes**  **No**

**6** Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \_\_\_\_\_

**7** Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \$ \_\_\_\_\_

**8** Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? . . . . .  **Yes**  **No**

**9** In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

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

**1a** If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

**b** If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenue included on Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

(ii) Assets included in Form 990, Part X . . . . . ▶ \$ \_\_\_\_\_

**2** If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

**a** Revenue included on Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

**b** Assets included in Form 990, Part X . . . . . ▶ \$ \_\_\_\_\_

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

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

**Part IV Escrow and Custodial Arrangements.**

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

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

**Part V Endowment Funds.**

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

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

**2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- a** Board designated or quasi-endowment ▶ .....
  - b** Permanent endowment ▶ .....
  - c** Term endowment ▶ .....
- The percentages on lines 2a, 2b, and 2c should equal 100%.

**3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

- (i)** Unrelated organizations . . . . .
- (ii)** Related organizations . . . . .

	Yes	No
<b>3a(i)</b>		
<b>3a(ii)</b>		
<b>3b</b>		

**b** If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? . . . . .

**4** Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment.**

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
<b>1a</b> Land . . . . .				
<b>b</b> Buildings . . . . .				
<b>c</b> Leasehold improvements				
<b>d</b> Equipment . . . . .				
<b>e</b> Other . . . . .				

**Total.** Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c.) . . . ▶



**Part VII Investments—Other Securities.**

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

Table with 3 columns: (a) Description of security or category, (b) Book value, (c) Method of valuation. Rows include (1) Financial derivatives, (2) Closely-held equity interests, (3) Other, (B) through (I), and Total.

**Part VIII Investments—Program Related.**

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

Table with 3 columns: (a) Description of investment, (b) Book value, (c) Method of valuation. Rows (2) through (10) and Total.

**Part IX Other Assets.**

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

Table with 2 columns: (a) Description, (b) Book value. Rows (2) through (10) and Total.

**Part X Other Liabilities.**

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

Table with 2 columns: (a) Description of liability, (b) Book value. Rows 1. Federal income taxes, (2) through (9), and Total.

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

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

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

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>		
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>		
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .		<b>5</b>	

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

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

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>		
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>		
<b>c</b>	Other losses . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .		<b>5</b>	

**Part XIII Supplemental Information**

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

Return Reference	Explanation

## **Additional Data**

[\*\*Return to Form\*\*](#)

**Software ID:**

**Software Version:**

**Supplemental Information Regarding  
Fundraising or Gaming Activities**

**2020**

**Open to Public  
Inspection**

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

▶ Attach to Form 990 or Form 990-EZ.

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

Department of the Treasury  
Internal Revenue Service

Name of the organization  
COALITION FOR USHER SYNDROME  
RESEARCH INCORPORATED

**Employer identification number**  
26-4560897

**Part I Fundraising Activities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 17.  
Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- |  |   |
|--|---|
| <b>a</b> <input type="checkbox"/> Mail solicitations               | <b>e</b> <input type="checkbox"/> Solicitation of non-government grants |
| <b>b</b> <input type="checkbox"/> Internet and email solicitations | <b>f</b> <input type="checkbox"/> Solicitation of government grants     |
| <b>c</b> <input type="checkbox"/> Phone solicitations              | <b>g</b> <input type="checkbox"/> Special fundraising events            |
| <b>d</b> <input type="checkbox"/> In-person solicitations          |   |
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  Yes  No
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
<b>Total</b>						

**3** List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

**Part II Fundraising Events.** Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

Revenue	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
	<b>ANNUAL APPEAL O</b> (event type)	(event type)	(total number)	(add col. (a) through col. (c))
<b>1</b> Gross receipts . . . . .	49,117			49,117
<b>2</b> Less: Contributions . . . . .	49,117			49,117
<b>3</b> Gross income (line 1 minus line 2) . . . . .				
Direct Expenses	<b>4</b> Cash prizes . . . . .			
	<b>5</b> Noncash prizes . . . . .			
	<b>6</b> Rent/facility costs . . . . .			
	<b>7</b> Food and beverages . . . . .			
	<b>8</b> Entertainment . . . . .			
	<b>9</b> Other direct expenses . . . . .			
<b>10</b> Direct expense summary. Add lines 4 through 9 in column (d) . . . . . ▶				
<b>11</b> Net income summary. Subtract line 10 from line 3, column (d) . . . . . ▶				

**Part III Gaming.** Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

Revenue	(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col.(a) through col.(c))
	<b>1</b> Gross revenue . . . . .			
Direct Expenses	<b>2</b> Cash prizes . . . . .			
	<b>3</b> Noncash prizes . . . . .			
	<b>4</b> Rent/facility costs . . . . .			
	<b>5</b> Other direct expenses . . . . .			
	<b>6</b> Volunteer labor . . . . .	<input type="checkbox"/> Yes _____ % .. <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % .. <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % .. <input type="checkbox"/> No
<b>7</b> Direct expense summary. Add lines 2 through 5 in column (d) . . . . . ▶				
<b>8</b> Net gaming income summary. Subtract line 7 from line 1, column (d) . . . . . ▶				

**9** Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_

**a** Is the organization licensed to conduct gaming activities in each of these states? . . . . .  Yes  No

**b** If "No," explain: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**10a** Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? . . . . .  Yes  No

**b** If "Yes," explain: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**11** Does the organization conduct gaming activities with nonmembers?  Yes  No

**12** Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?  Yes  No

**13** Indicate the percentage of gaming activity conducted in:

<b>a</b> The organization's facility	<b>13a</b>	%
<b>b</b> An outside facility	<b>13b</b>	%

**14** Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ -----

Address ▶ -----

**15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue?  Yes  No

**b** If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ \_\_\_\_\_ and the amount of gaming revenue retained by the third party ▶ \$ \_\_\_\_\_.

**c** If "Yes," enter name and address of the third party:

Name ▶ -----

Address ▶ -----

**16** Gaming manager information:

Name ▶ -----

Gaming manager compensation ▶ \$ -----

Description of services provided ▶ -----

Director/officer       Employee       Independent contractor

**17** Mandatory distributions:

**a** Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?  Yes  No

**b** Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ \_\_\_\_\_

<b>Part IV Supplemental Information.</b> Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See Instructions.	
Return Reference	Explanation

**SCHEDULE O**  
**(Form 990 or 990-EZ)**Department of the Treasury  
Internal Revenue Service**Supplemental Information to Form 990 or 990-EZ****Complete to provide information for responses to specific questions on  
Form 990 or 990-EZ or to provide any additional information.****▶ Attach to Form 990 or 990-EZ.****▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.**

OMB No. 1545-0047

**2020****Open to Public  
Inspection**Name of the organization  
COALITION FOR USHER SYNDROME  
RESEARCH INCORPORATED**Employer identification number**

26-4560897

<b>Return Reference</b>	<b>Explanation</b>
FORM 990, PAGE 2, PART III, LINE 4D	RAISE AWARENESS AND ACCELERATE RESEARCH FOR THE MOST COMMON CAUSE OF COMBINED DEAFNESS AND BLINDNESS. PROVIDE INFORMATION AND SUPPORT TO INDIVIDUALS AND FAMILIES AFFECTED BY USHER SYNDROME.
FORM 990, PAGE 6, PART VI, LINE 11B	A COPY OF THE FORM 990 IS REVIEWED BY THE PRESIDENT AND EXECUTIVE DIRECTOR BEFORE IT IS SIGNED.
FORM 990, PAGE 6, PART VI, LINE 12C	BOARD MEMBERS ARE PROVIDED AND MUST RETURN SIGNED CONFLICT OF INTEREST DISCLOSURE FORMS ANNUALLY.
FORM 990, PAGE 6, PART VI, LINE 19	THE GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICIES AND THE FINANCIAL STATEMENTS ARE AVAILABLE TO THE PUBLIC UPON REQUEST.

## **Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**