

Form **990**

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2022

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

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

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

A For the 2022 calendar year, or tax year beginning 01-01-2022, and ending 12-31-2022

- 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

Doing business as

Number and street (or P.O. box if mail is not delivered to street address) Room/suite
9 Cornerstone Square STE 400-224

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
(800) 946-9203

G Gross receipts \$ 502,883

F Name and address of principal officer:
Lanya McKittrick
63 Great Road Suite 207
Maynard, MA 01754

H(a) Is this a group return for subordinates? Yes No

H(b) Are all subordinates included? Yes No
If "No," attach a list. See instructions.

H(c) Group exemption number ▶

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

J Website: ▶ <https://www.usher-syndrome.org/>

K Form of organization: Corporation Trust Association Other ▶

L Year of formation: 2009

M State of legal domicile:
MA

Part I Summary

| | | | | | |
|--|--|---------------------------|---------|--------------|---------|
| Activities & Governance | 1 Briefly describe the organization's mission or most significant activities: To raise awareness and accelerate research for the most common genetic cause of combined deafness and blindness, while providing information and support to individuals with Usher syndrome. | | | | |
| | 2 Check this box <input type="checkbox"/> | | | | |
| | 3 Number of voting members of the governing body (Part VI, line 1a) | 3 | 13 | | |
| | 4 Number of independent voting members of the governing body (Part VI, line 1b) | 4 | 13 | | |
| | 5 Total number of individuals employed in calendar year 2022 (Part V, line 2a) | 5 | 3 | | |
| | 6 Total number of volunteers (estimate if necessary) | 6 | 75 | | |
| | 7a Total unrelated business revenue from Part VIII, column (C), line 12 | 7a | 0 | | |
| | b Net unrelated business taxable income from Form 990-T, Part I, line 11 | 7b | | | |
| Revenue | 8 Contributions and grants (Part VIII, line 1h) | Prior Year | 61,265 | Current Year | 393,749 |
| | 9 Program service revenue (Part VIII, line 2g) | | 128,110 | | 109,132 |
| | 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) | | 2 | | 2 |
| | 11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) | | | | 0 |
| | 12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) | | 189,377 | | 502,883 |
| Expenses | 13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) | | | | 404 |
| | 14 Benefits paid to or for members (Part IX, column (A), line 4) | | | | 0 |
| | 15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) | | 92,436 | | 215,580 |
| | 16a Professional fundraising fees (Part IX, column (A), line 11e) | | | | 0 |
| | b Total fundraising expenses (Part IX, column (D), line 25) ▶ 0 | | | | |
| | 17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) | | 99,462 | | 199,767 |
| | 18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) | | 191,898 | | 415,751 |
| 19 Revenue less expenses. Subtract line 18 from line 12 | | -2,521 | | 87,132 | |
| Net Assets or Fund Balances | 20 Total assets (Part X, line 16) | Beginning of Current Year | 197,279 | End of Year | 286,985 |
| | 21 Total liabilities (Part X, line 26) | | 1,190 | | 3,764 |
| | 22 Net assets or fund balances. Subtract line 21 from line 20 | | 196,089 | | 283,221 |

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 | | 2023-11-15 | | |
| | Lanya McKittrick President | | Date | | |
| Paid Preparer Use Only | Print/Type preparer's name | Preparer's signature | Date 2023-11-15 | Check <input type="checkbox"/> if self-employed | PTIN P02188892 |
| | Firm's name ▶ Foundation Group Inc | | | Firm's EIN ▶ 62-1813735 | |
| | Firm's address ▶ 2451 Atrium Way Suite 300 Nashville, TN 37214 | | | Phone no. (615) 361-9445 | |
| | | | | | |

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

For Paperwork Reduction Act Notice, see the separate instructions. Cat. No. 11282Y Form **990** (2022)

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:
 To raise awareness and accelerate research for the most common genetic cause of combined deafness and blindness, while providing information and support to individuals with 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 \$ **404,572** including grants of \$ **404**) (Revenue \$ **109,132**)
 The organization raises awareness and accelerates research for the most common cause of combined deafness and blindness, while providing information and support to individuals with Usher syndrome. This is accomplished through their connections conference where attendees have the opportunity to learn the latest on developing treatments while connecting with other affected individuals and families. The organization also connects others affected by Usher syndrome to help provide a community form them and their families.

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

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

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

4e Total program service expenses 404,572

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, and Yes/No response columns. Contains 20a-20a questions regarding organizational requirements.

| | | | | |
|----|--|-----|--|----|
| b | If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? | 20b | | |
| 21 | Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> | 21 | | No |

Part IV Checklist of Required Schedules (continued)

| | | Yes | No |
|-----|--|-----|-----|
| 22 | Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i> | 22 | No |
| 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? <i>If "Yes," complete Schedule J</i> | 23 | No |
| 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? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> | 24a | No |
| b | Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? | 24b | |
| c | Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? | 24c | |
| d | Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? | 24d | |
| 25a | Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i> | 25a | No |
| 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? <i>If "Yes," complete Schedule L, Part I</i> | 25b | No |
| 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 of any of these persons? <i>If "Yes," complete Schedule L, Part II</i> | 26 | No |
| 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? <i>If "Yes," complete Schedule L, Part III</i> | 27 | No |
| 28 | Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions): | | |
| a | A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i> | 28a | No |
| b | A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i> | 28b | No |
| c | A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i> | 28c | No |
| 29 | Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> | 29 | No |
| 30 | Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i> | 30 | No |
| 31 | Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> | 31 | No |
| 32 | Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i> | 32 | No |
| 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? <i>If "Yes," complete Schedule R, Part I</i> | 33 | No |
| 34 | Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i> | 34 | No |
| 35a | Did the organization have a controlled entity within the meaning of section 512(b)(13)? | 35a | No |
| 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)? <i>If "Yes," complete Schedule R, Part V, line 2</i> | 35b | |
| 36 | Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i> | 36 | No |
| 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? <i>If "Yes," complete Schedule R, Part VI</i> | 37 | No |
| 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 | Yes |

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

| | | | | | |
|---|-----------|-----|--|--|--|
| 1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable | 1a | 1 | | | |
| b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable | 1b | 0 | | | |
| c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? | 1c | Yes | | | |

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

| | | | | | |
|--|------------|-----|----|--|--|
| 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 | 3 | | | |
| b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? | 2b | Yes | | | |
| 3a Did the organization have unrelated business gross income of \$1,000 or more during the year? | 3a | | No | | |
| b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in 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 | | No | | |
| 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 | | No | | |
| b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? | 5b | | No | | |
| c 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 | | No | | |
| 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). | | | | | |
| a 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 | | No | | |
| b If "Yes," did the organization notify the donor of the value of the goods or services provided? | 7b | | | | |
| c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? | 7c | | No | | |
| d If "Yes," indicate the number of Forms 8282 filed during the year | 7d | | | | |
| e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? | 7e | | No | | |
| f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? | 7f | | No | | |
| 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. | | | | | |
| a 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: | | | | | |
| a Initiation fees and capital contributions included on Part VIII, line 12 | 10a | | | | |
| 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: | | | | | |
| a 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.) | 11b | | | | |
| 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. | 12b | | | | |
| 13 Section 501(c)(29) qualified nonprofit health insurance issuers. | | | | | |
| a Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O. | 13a | | | | |
| b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans | 13b | | | | |

| | | | |
|-----|--|-----|----|
| 13b | | | |
| c | Enter the amount of reserves on hand | 13c | |
| 14a | Did the organization receive any payments for indoor tanning services during the tax year? | 14a | No |
| b | If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in 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? If "Yes," see the instructions and file Form 4720, Schedule N. | 15 | No |
| 16 | Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O. | 16 | No |
| 17 | Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069. | 17 | |

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Form 990 (2022)

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

| | | 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 in Schedule O. | 13 | |
| b | Enter the number of voting members included in line 1a, above, who are independent | 13 | |
| 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 | No |
| 3 | Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? | 3 | No |
| 4 | Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? | 4 | No |
| 5 | Did the organization become aware during the year of a significant diversion of the organization's assets? | 5 | No |
| 6 | Did the organization have members or stockholders? | 6 | No |
| 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 | No |
| 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 | No |
| 8 | Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: | | |
| a | The governing body? | 8a | Yes |
| b | Each committee with authority to act on behalf of the governing body? | 8b | Yes |
| 9 | Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O | 9 | No |

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

| | | Yes | No |
|-----|--|-----|-----|
| 10a | Did the organization have local chapters, branches, or affiliates? | 10a | No |
| b | If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? | 10b | |
| 11a | Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? | 11a | Yes |
| b | Describe on Schedule O the process, if any, used by the organization to review this Form 990. | | |
| 12a | Did the organization have a written conflict of interest policy? If "No," go to line 13 | 12a | Yes |
| b | Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? | 12b | Yes |
| c | Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done | 12c | Yes |
| 13 | Did the organization have a written whistleblower policy? | 13 | Yes |
| 14 | Did the organization have a written document retention and destruction policy? | 14 | Yes |
| 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 | No |
| b | Other officers or key employees of the organization | 15b | No |
| | If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. | | |

| | | |
|---|------------|----|
| 10a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? | 16a | No |
| b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? | 16b | |

Section C. Disclosure

- 17** List the states with which a copy of this Form 990 is required to be filed **MA, NY**
- 18** Section 6104 requires an organization to make its Form 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 Upon request Other (explain in Schedule O)
- 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:
Foundation Group Inc 2451 Atrium Way Suite 300 Nashville, TN 37214 (615) 361-9445

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 the instructions for definition of "key employee."
 - List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
 - List all of the organization's **former** officers, key employees, 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 the instructions for the order in which to list the persons above.

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

| (A) Name and title | (B) Average hours per week (list any hours for related organizations below dotted line) | (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) | | | | | (D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC) | (E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC) | (F) Estimated amount of other compensation from the organization and related organizations |
|--|--|---|------------------------|---------|--------------|------------------------------|---|--|---|
| | | Individual trustee or director | Institutional Trustee; | Officer | Key employee | Highest compensated employee | | | |
| (1) Lanya McKittrick PhD President | 1.00 | X | | X | | | 0 | 0 | 0 |
| (2) David Alexander Director | 1.00 | X | | | | | 0 | 0 | 0 |
| (3) Danay Trest Director | 1.00 | X | | | | | 0 | 0 | 0 |
| (4) Kathy Anamisis Director | 1.00 | X | | | | | 0 | 0 | 0 |
| (5) Kelley Stidd Director | 1.00 | X | | | | | 0 | 0 | 0 |
| (6) Margaret Kenna MD MPH Director | 1.00 | X | | | | | 0 | 0 | 0 |
| (7) Monte Westerfield PhD Director | 1.00 | X | | | | | 0 | 0 | 0 |

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

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

Section B. Independent Contractors

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


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

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

Part VIII **Statement of Revenue**

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

| | (A) Total revenue | (B) Related or exempt function revenue | (C) Unrelated business revenue | (D) Revenue excluded from tax under sections 512 - 514 |
|--|----------------------|---|-----------------------------------|---|
|--|----------------------|---|-----------------------------------|---|

-  Federated campaigns . . . **1a**
- Contributions, Gifts, Grants, and Membership dues . . . **1b**
- Other Amounts Similar to Fundraising events . . . **1c**
- d** Related organizations **1d**
- e** Government grants (contributions) **1e**
- f** All other contributions, gifts, grants, and similar amounts not included above **1f**
- 393,749
- g** Noncash contributions included in lines 1a - 1f: \$ **1g**
- h Total.** Add lines 1a-1f ▶ 393,749

| 2a | Business Code | | | |
|--------------------|---------------|---------|---------|--|
| Conference Revenue | 900099 | 109,132 | 109,132 | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

Program Service Revenue

| | | | | | |
|---|---------------|----------------|---------------|--|---|
| r All other program service revenue. | | | | | |
| 9 Total. Add lines 2a-2f. ▶ | | 109,132 | | | |
| 3 Investment income (including dividends, interest, and other similar amounts) ▶ | | | 2 | | 2 |
| 4 Income from investment of tax-exempt bond proceeds ▶ | | | | | |
| 5 Royalties ▶ | | | | | |
| | | (i) Real | (ii) Personal | | |
| 6a Gross rents | 6a | | | | |
| b Less: rental expenses | 6b | | | | |
| c Rental income or (loss) | 6c | | | | |
| d Net rental income or (loss) ▶ | | | | | |
| | | (i) Securities | (ii) Other | | |
| 7a Gross amount from sales of assets other than inventory | 7a | | | | |
| Less: cost or other basis and sales expenses | 7b | | | | |
| Gain or (loss) | 7c | | | | |
| d Net gain or (loss) ▶ | | | | | |
| a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18 | 8a | | | | |
| b Less: direct expenses | 8b | | | | |
| c Net income or (loss) from fundraising events ▶ | | | | | |
| 9a Gross income from gaming activities. See Part IV, line 19 | 9a | | | | |
| b Less: direct expenses | 9b | | | | |
| c Net income or (loss) from gaming activities ▶ | | | | | |
| 10a Gross sales of inventory, less returns and allowances | 10a | | | | |
| b Less: cost of goods sold | 10b | | | | |
| c Net income or (loss) from sales of inventory ▶ | | | | | |
| 11a | Business Code | | | | |
| b | | | | | |
| Other Revenue Misc Amt | | | | | |
| d All other revenue | | | | | |
| e Total. Add lines 11a-11d ▶ | | | | | |
| 12 Total revenue. See instructions ▶ | | 502,883 | 109,132 | | 2 |

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

| | | | | |
|---|------------------------------|--|---|------------------------------------|
| Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII. | (A) Total expenses | (B) Program service expenses | (C) Management and general expenses | (D) Fundraising expenses |
|---|------------------------------|--|---|------------------------------------|

| | | | | |
|--|---------|---------|--------|---|
| 1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 | 0 | | | |
| 2 Grants and other assistance to domestic individuals. See Part IV, line 22 | 404 | 404 | | |
| 3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16. | 0 | | | |
| 4 Benefits paid to or for members | 0 | | | |
| 5 Compensation of current officers, directors, trustees, and key employees | 0 | | | |
| 6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) | 0 | | | |
| 7 Other salaries and wages | 204,532 | 204,532 | | |
| 8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) | 0 | | | |
| 9 Other employee benefits | 5,554 | 5,554 | | |
| 10 Payroll taxes | 5,494 | 5,494 | | |
| 11 Fees for services (non-employees): | | | | |
| a Management | 5,770 | | 5,770 | |
| b Legal | 188 | | 188 | |
| c Accounting | 2,128 | 1,528 | 600 | |
| d Lobbying | 0 | | | |
| e Professional fundraising services. See Part IV, line 17 | | | | |
| f Investment management fees | 0 | | | |
| g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O) | 400 | 400 | | |
| 12 Advertising and promotion | 1,899 | 1,899 | | |
| 13 Office expenses | 5,678 | 1,057 | 4,621 | |
| 14 Information technology | 944 | 944 | | |
| 15 Royalties | 0 | | | |
| 16 Occupancy | 913 | 913 | | |
| 17 Travel | 4,606 | 4,606 | | |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials | 0 | | | |
| 19 Conferences, conventions, and meetings | 0 | | | |
| 20 Interest | 0 | | | |
| 21 Payments to affiliates | 0 | | | |
| 22 Depreciation, depletion, and amortization | 0 | | | |
| 23 Insurance | 1,502 | 1,502 | | |
| 24 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.) | | | | |
| a Program Expense Conference and Workshops | 160,490 | 160,490 | | |
| b Program Expense Outreach Registry Development | 15,024 | 15,024 | | |
| c Program Expense USH Talks Video Recording | 175 | 175 | | |
| d Volunteer Appreciation | 50 | 50 | | |
| e All other expenses | 0 | | | |
| 25 Total functional expenses. Add lines 1 through 24e | 415,751 | 404,572 | 11,179 | 0 |
| 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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720). | | | | |

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

| | | (A) Beginning of year | | (B) End of year |
|---|--|--------------------------|-----------|--------------------|
| Assets | 1 Cash-non-interest-bearing | 187,429 | 1 | 253,348 |
| | 2 Savings and temporary cash investments | | 2 | 20,803 |
| | 3 Pledges and grants receivable, net | | 3 | |
| | 4 Accounts receivable, net | 9,850 | 4 | 9,850 |
| | 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 | |
| | 7 Notes and loans receivable, net | | 7 | |
| | 8 Inventories for sale or use | | 8 | |
| | 9 Prepaid expenses and deferred charges | | 9 | 2,984 |
| | 10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D | 10a | | |
| | b Less: accumulated depreciation | 10b | | 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) | 197,279 | 16 | 286,985 | |
| Liabilities | 17 Accounts payable and accrued expenses | 1,190 | 17 | 3,764 |
| | 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 | |
| | 22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons | | 22 | |
| | 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 | 1,190 | 26 | 3,764 |
| Net Assets or Fund Balances | Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33. | | | |
| | 27 Net assets without donor restrictions | 196,089 | 27 | 283,221 |
| | 28 Net assets with donor restrictions | | 28 | |
| | Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33. | | | |
| | 29 Capital stock or trust principal, or current funds | | 29 | |
| | 30 Paid-in or capital surplus, or land, building or equipment fund | | 30 | |
| | 31 Retained earnings, endowment, accumulated income, or other funds | | 31 | |
| | 32 Total net assets or fund balances | 196,089 | 32 | 283,221 |
| 33 Total liabilities and net assets/fund balances | 197,279 | 33 | 286,985 | |

Form 990 (2022)

Part 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 | 502,883 |
| 2 Total expenses (must equal Part IX, column (A), line 25) | 2 | 415,751 |
| 3 Revenue less expenses. Subtract line 2 from line 1 | 3 | 87,132 |

| | | | |
|----|--|----|---------|
| 4 | Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) | 4 | 196,089 |
| 5 | Net unrealized gains (losses) on investments | 5 | |
| 6 | Donated services and use of facilities | 6 | |
| 7 | Investment expenses | 7 | |
| 8 | Prior period adjustments | 8 | |
| 9 | Other changes in net assets or fund balances (explain in Schedule O) | 9 | |
| 10 | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B)) | 10 | 283,221 |

Part XII **Financial Statements and Reporting**

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

| | | Yes | No |
|-----------|---|-----|----|
| 1 | Accounting method used to prepare the Form 990: <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 on Schedule O. | | |
| 2a | 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 type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis | | No |
| 2b | 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 |
| 2c | 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. | | |
| 3a | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F? | | No |
| 3b | 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. | | |

Form 990 (2022)

Form 990 (2022)

Additional Data

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Software ID: 22015461

Software Version: 22.0.1.0

Form 990, Special Condition Description:

Special Condition Description

SCHEDULE A
(Form 990)

Department of the Treasury
Internal Revenue Service

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

OMB No. 1545-0047
2022
Open to Public Inspection

| | |
|--|---|
| Name of the organization Coalition For Usher Syndrome Research | 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).)
- 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 on 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 | | |
| | | | | | | |
| Total | | | | | | |

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

Section A. Public Support

| | | | | | | |
|---------------|--|--|--|--|--|--|
| Calendar year | | | | | | |
|---------------|--|--|--|--|--|--|

| Calendar year (or fiscal year beginning in) ▶ | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . . | | | | | | |
| 2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf. . . . | | | | | | |
| 3 The value of services or facilities furnished by a governmental unit to the organization without charge.. | | | | | | |
| 4 Total. Add lines 1 through 3 | | | | | | |
| 5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) . . . | | | | | | |
| 6 Public support. Subtract line 5 from line 4. | | | | | | |

Section B. Total Support

| Calendar year (or fiscal year beginning in) ▶ | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| 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, whether or not the business is regularly carried on. . | | | | | | |
| 10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . | | | | | | |
| 11 Total support. Add lines 7 through 10 | | | | | | |

12 Gross receipts from related activities, etc. (see instructions) **12**

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

Section C. Computation of Public Support Percentage

| | | |
|--|-----------|--|
| 14 Public support percentage for 2022 (line 6, column (f) divided by line 11, column (f)) | 14 | |
| 15 Public support percentage for 2021 Schedule A, Part II, line 14 | 15 | |

- 16a 33 1/3% support test—2022.** If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization
- b 33 1/3% support test—2021.** If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization
- 17a 10%-facts-and-circumstances test—2022.** If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization
- b 10%-facts-and-circumstances test—2021.** If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization
- 18 Private foundation.** If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions

Schedule A (Form 990) 2022

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) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
|---|----------|----------|----------|----------|----------|-----------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") . . . | 199,266 | 221,168 | 208,070 | 61,265 | 393,749 | 1,083,518 |
| 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 | | 58,892 | 28,681 | 128,110 | 109,132 | 324,815 |
| 3 Gross receipts from activities that are not an unrelated trade or business under section 513 | | | | | | |
| 4 Tax revenues levied for the | | | | | | |

| | | | | | | | |
|----|---|---------|---------|---------|---------|---------|-----------|
| 5 | organization's benefit and either paid to or expended on its behalf. The value of services or facilities furnished by a governmental unit to the organization without charge | | | | | | |
| 6 | Total. Add lines 1 through 5 | 199,266 | 280,060 | 236,751 | 189,375 | 502,881 | 1,408,333 |
| 7a | Amounts included on lines 1, 2, and 3 received from disqualified persons | | | | 10,552 | 13,646 | 24,198 |
| 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. | | | | | 58,661 | 58,661 |
| c | Add lines 7a and 7b. | | | | 10,552 | 72,307 | 82,859 |
| 8 | Public support. (Subtract line 7c from line 6.) | | | | | | 1,325,474 |

Section B. Total Support

| Calendar year (or fiscal year beginning in) ▶ | (a) 2018 | (b) 2019 | (c) 2020 | (d) 2021 | (e) 2022 | (f) Total |
|---|--|----------|----------|----------|----------|-----------|
| 9 | 199,266 | 280,060 | 236,751 | 189,375 | 502,881 | 1,408,333 |
| 10a | 7 | 4 | 3 | 2 | 2 | 18 |
| b | | | | | | 0 |
| c | 7 | 4 | 3 | 2 | 2 | 18 |
| 11 | | | | | | 0 |
| 12 | | | | | | 0 |
| 13 | 199,273 | 280,064 | 236,754 | 189,377 | 502,883 | 1,408,351 |
| 14 | First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here. <input type="checkbox"/> | | | | | |

Section C. Computation of Public Support Percentage

| | | | |
|----|--|----|----------|
| 15 | Public support percentage for 2022 (line 8, column (f) divided by line 13, column (f)) | 15 | 94.120 % |
| 16 | Public support percentage from 2021 Schedule A, Part III, line 15 | 16 | 99.070 % |

Section D. Computation of Investment Income Percentage

| | | | |
|----|--|----|-----|
| 17 | Investment income percentage for 2022 (line 10c, column (f) divided by line 13, column (f)) | 17 | 0 % |
| 18 | Investment income percentage from 2021 Schedule A, Part III, line 17 | 18 | |

- 19a **33 1/3% support tests—2022.** 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—2021.** 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

Schedule A (Form 990) 2022

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 |
|--|-----|----|
| 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 box 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 (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 line 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).

| | | |
|------------|--|--|
| 3c | | |
| 4a | | |
| 4b | | |
| 4c | | |
| 5a | | |
| 5b | | |
| 5c | | |
| 6 | | |
| 7 | | |
| 8 | | |
| 9a | | |
| 9b | | |
| 9c | | |
| 10a | | |
| 10b | | |

Schedule A (Form 990) 2022

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

| | Yes | No |
|---|-----|----|
| 1 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? 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. | | |
| 2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization. | | |

Section 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 D. All Type III Supporting Organizations

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

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.**

- a** 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.
- b** Did the activities described on line 2a, above constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in **Part VI** the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.

| | Yes | No |
|-----------|-----|----|
| 2a | | |
| 2b | | |
| 3a | | |
| 3b | | |

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

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

Schedule A (Form 990) 2022

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) |
|---|-----------|----------------|-----------------------------|
| 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 | | |
| Section 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): | 1 | | |
| a Average monthly value of securities | 1a | | |
| b Average monthly cash balances | 1b | | |
| c Fair market value of other non-exempt-use assets | 1c | | |
| d Total (add lines 1a, 1b, and 1c) | 1d | | |
| e Discount claimed for blockage or other factors | | | |

| | | | |
|---|--|----------|--------------|
| <input type="checkbox"/> Exempt claimed for coverage of other factors (explain in detail in Part VI): | | | |
| 2 | Acquisition indebtedness applicable to non-exempt use assets | 2 | |
| 3 | Subtract line 2 from line 1d | 3 | |
| 4 | Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions). | 4 | |
| 5 | Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | |
| 6 | Multiply line 5 by 0.035 | 6 | |
| 7 | Recoveries of prior-year distributions | 7 | |
| 8 | Minimum Asset Amount (add line 7 to line 6) | 8 | |
| Section C - Distributable Amount | | | Current Year |
| 1 | Adjusted net income for prior year (from Section A, line 8, Column A) | 1 | |
| 2 | Enter 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 | <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions) | | |

Schedule A (Form 990) 2022

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

| Section D - Distributions | | Current Year | |
|----------------------------------|---|---------------------|--|
| 1 | Amounts paid to supported organizations to accomplish exempt purposes | 1 | |
| 2 | Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity | 2 | |
| 3 | Administrative expenses paid to accomplish exempt purposes of supported organizations | 3 | |
| 4 | Amounts paid to acquire exempt-use assets | 4 | |
| 5 | Qualified set-aside amounts (prior IRS approval required - provide details in Part VI) | 5 | |
| 6 | Other distributions (describe in Part VI). See instructions | 6 | |
| 7 | Total annual distributions. Add lines 1 through 6. | 7 | |
| 8 | Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions | 8 | |
| 9 | Distributable amount for 2022 from Section C, line 6 | 9 | |
| 10 | Line 8 amount divided by Line 9 amount | 10 | |

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

| | | | |
|--|--|--|--|
| d Applied to 2022 distributable amount | | | |
| c Remainder. Subtract lines 4a and 4b from line 4. | | | |
| 5 Remaining underdistributions for years prior to 2022, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions. | | | |
| 6 Remaining underdistributions for 2022. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions. | | | |
| 7 Excess distributions carryover to 2023. Add lines 3j and 4c. | | | |
| 8 Breakdown of line 7: | | | |
| a Excess from 2018. | | | |
| b Excess from 2019. | | | |
| c Excess from 2020. | | | |
| d Excess from 2021. | | | |
| e Excess from 2022. | | | |

Schedule A (Form 990) (2022)

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

Schedule A (Form 990) 2022

Additional Data

Return to Form

Software ID: 22015461
Software Version: 22.0.1.0

Schedule B

Schedule of Contributors

OMB No. 1545-0047

(Form 990) Department of the Treasury Internal Revenue Service

Attach to Form 990, 990-EZ, or 990-PF. Go to www.irs.gov/Form990 for the latest information.

2022

Table with 2 columns: Name of the organization (Coalition For Usher Syndrome Research) and Employer identification number (26-4560897)

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 1/3% support test...
For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor...
For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor...

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).

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.) |
| - | | \$ | <input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.) |
| - | | \$ | <input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.) |
| - | | \$ | <input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.) |
| - | | \$ | <input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.) |
| - | | \$ | <input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.) |
| - | | \$ | <input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.) |

Schedule B (Form 990) (2022)

| | |
|---|--|
| Name of organization Coalition For Usher Syndrome Research | 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 |
|------------------------|--|--|----------------------|
|------------------------|--|--|----------------------|

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

Schedule B (Form 990) (2022)

Schedule B (Form 990) (2022)

| | |
|---|--|
| Name of organization Coalition For Usher Syndrome Research | Employer identification number 26-4560897 |
|---|--|

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 |

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

Schedule B (Form 990) (2022)

Additional Data

[Return to Form](#)

Software ID: 22015461
Software Version: 22.0.1.0

SCHEDULE C
(Form 990)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

OMB No. 1545-0047

For Organizations Exempt From Income Tax Under section 501(c) and section 527

2022

Open to Public Inspection

▶ **Complete if the organization is described below.** ▶ Attach to Form 990 or Form 990-EZ.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

If the organization answered "Yes" on Form 990, Part IV, Line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes" on Form 990, Part IV, Line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes" on Form 990, Part IV, Line 5 (Proxy Tax) (see separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

| | |
|---|--|
| Name of the organization Coalition For Usher Syndrome Research | Employer identification number 26-4560897 |
|---|--|

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV. See instructions for definition of "political campaign activities."
- 2 Political campaign activity expenditures. See instructions ▶ \$ _____
- 3 Volunteer hours for political campaign activities. See instructions

Part I-B Complete if the organization is exempt under section 501(c)(3).

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ \$ _____
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$ _____
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? Yes No
- 4a Was a correction made? Yes No
- b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ \$ _____
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ \$ _____
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b..... ▶ \$ _____
- 4 Did the filing organization file **Form 1120-POL** for this year? Yes No
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

| (a) Name | (b) Address | (c) EIN | (d) Amount paid from filing organization's funds. If none, enter -0-. | (e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-. |
|----------|-------------|---------|---|--|
| 1 | | | | |
| 2 | | | | |
| 3 | | | | |
| 4 | | | | |
| 5 | | | | |
| 6 | | | | |

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

Section 501(h).

- A** Check if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).
- B** Check if the filing organization checked box A and "limited control" provisions apply.

| Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.) | (a) Filing organization's totals | (b) Affiliated group totals | | | | | | | | | | | | |
|--|--|--|--------------------|-------------------------------|---|--|---|--|--|---|-------------------|--------------|--|--|
| 1a Total lobbying expenditures to influence public opinion (grass roots lobbying) | | | | | | | | | | | | | | |
| b Total lobbying expenditures to influence a legislative body (direct lobbying) | | | | | | | | | | | | | | |
| c Total lobbying expenditures (add lines 1a and 1b) | | | | | | | | | | | | | | |
| d Other exempt purpose expenditures | | | | | | | | | | | | | | |
| e Total exempt purpose expenditures (add lines 1c and 1d) | | | | | | | | | | | | | | |
| f Lobbying nontaxable amount. Enter the amount from the following table in both columns. | | | | | | | | | | | | | | |
| <table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th style="width:35%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width:65%;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table> | If the amount on line 1e, column (a) or (b) is: | The lobbying nontaxable amount is: | Not over \$500,000 | 20% of the amount on line 1e. | Over \$500,000 but not over \$1,000,000 | \$100,000 plus 15% of the excess over \$500,000. | Over \$1,000,000 but not over \$1,500,000 | \$175,000 plus 10% of the excess over \$1,000,000. | Over \$1,500,000 but not over \$17,000,000 | \$225,000 plus 5% of the excess over \$1,500,000. | Over \$17,000,000 | \$1,000,000. | | |
| If the amount on line 1e, column (a) or (b) is: | The lobbying nontaxable amount is: | | | | | | | | | | | | | |
| Not over \$500,000 | 20% of the amount on line 1e. | | | | | | | | | | | | | |
| Over \$500,000 but not over \$1,000,000 | \$100,000 plus 15% of the excess over \$500,000. | | | | | | | | | | | | | |
| Over \$1,000,000 but not over \$1,500,000 | \$175,000 plus 10% of the excess over \$1,000,000. | | | | | | | | | | | | | |
| Over \$1,500,000 but not over \$17,000,000 | \$225,000 plus 5% of the excess over \$1,500,000. | | | | | | | | | | | | | |
| Over \$17,000,000 | \$1,000,000. | | | | | | | | | | | | | |
| g Grassroots nontaxable amount (enter 25% of line 1f) | | | | | | | | | | | | | | |
| h Subtract line 1g from line 1a. If zero or less, enter -0- | | | | | | | | | | | | | | |
| i Subtract line 1f from line 1c. If zero or less, enter -0- | | | | | | | | | | | | | | |
| j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? | | <input type="checkbox"/> Yes <input type="checkbox"/> No | | | | | | | | | | | | |

4-Year Averaging Period Under Section 501(h)
(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

| Lobbying Expenditures During 4-Year Averaging Period | | | | | |
|--|----------|----------|----------|----------|-----------|
| Calendar year (or fiscal year beginning in) | (a) 2019 | (b) 2020 | (c) 2021 | (d) 2022 | (e) Total |
| 2a Lobbying nontaxable amount | | | | | |
| b Lobbying ceiling amount (150% of line 2a, column(e)) | | | | | |
| c Total lobbying expenditures | | | | | |
| d Grassroots nontaxable amount | | | | | |
| e Grassroots ceiling amount (150% of line 2d, column (e)) | | | | | |
| f Grassroots lobbying expenditures | | | | | |

Schedule C (Form 990) 2022

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

| | (a) | | (b) |
|--|-----|----|--------|
| | Yes | No | Amount |
| 1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of: | | | |
| a Volunteers? | Yes | | |
| b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? | Yes | | |
| c Media advertisements? | | No | |
| d Mailings to members, legislators, or the public? | | No | |
| e Publications or published or broadcast statements? | | No | |

| | | | | |
|----|---|-----|----|-------|
| c | Publications, or published or broadcast statements? | | No | |
| f | Grants to other organizations for lobbying purposes? | | No | |
| g | Direct contact with legislators, their staffs, government officials, or a legislative body? | Yes | | 1,000 |
| h | Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? | | No | |
| i | Other activities? | | No | |
| j | Total. Add lines 1c through 1i | | | 1,000 |
| 2a | Did the activities in line 1 cause the organization to be not described in section 501(c)(3)? | | No | |
| b | If "Yes," enter the amount of any tax incurred under section 4912 | | | |
| c | If "Yes," enter the amount of any tax incurred by organization managers under section 4912 | | | |
| d | If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year? | | No | |

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

| | Yes | No |
|---|-----|----|
| 1 Were substantially all (90% or more) dues received nondeductible by members? | 1 | |
| 2 Did the organization make only in-house lobbying expenditures of \$2,000 or less? | 2 | |
| 3 Did the organization agree to carry over lobbying and political expenditures from the prior year? | 3 | |

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

| | | |
|--|----|--|
| 1 Dues, assessments and similar amounts from members | 1 | |
| 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). | | |
| a Current year | 2a | |
| b Carryover from last year | 2b | |
| c Total | 2c | |
| 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues . | 3 | |
| 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year? | 4 | |
| 5 Taxable amount of lobbying and political expenditures. See Instructions | 5 | |

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions), and Part II-B, line 1. Also, complete this part for any additional information.

| Return Reference | Explanation |
|------------------|---|
| II-B 1a, 1b, 1g | The organization sends volunteers and some staff for one day to Capital Hill to speak to legislators in order to raise awareness and advocate for those affect by Usher Syndrome. The 1,000 was travel expenses for the volunteers and staff. |

Schedule C (Form 990) 2022

Additional Data

Return to Form

Software ID: 22015461
Software Version: 22.0.1.0

SCHEDULE O
(Form 990)

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 for the latest information.

OMB No. 1545-0047

2022

Open to Public Inspection

Name of the organization
Coalition For Usher Syndrome Research

Employer identification number

26-4560897

| Return Reference | Explanation |
|--|---|
| Form 990, Part VI, Section B, Line 11b | The organization reviews the 990 form at a board meeting prior to submitting to the IRS. |
| Form 990, Part VI, Section B, Line 12c | The organization enforced compliance with its conflict of interest policy by reviewing it periodically at board meetings. |
| Form 990, Part VI, Section C, Line 19 | The organization makes its governing documents, conflict of interest policy, and financial statements available to the public upon request. |

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

Cat. No. 51056K

Schedule O (Form 990) 2022

Additional Data

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Software ID: 22015461

Software Version: 22.0.1.0