

# TAX RETURN FILING INSTRUCTIONS

FORM 990

**FOR THE YEAR ENDING**  
DECEMBER 31, 2024

|   |  |
|---|--|
| <b>Prepared for</b>                                 | CREUTZFELDT-JAKOB DISEASE FOUNDATION INC<br>3634 WEST MARKET STREET 110<br>AKRON, OH 44333   |
| <b>Prepared by</b>                                  | CIUNI & PANICHI, INC.<br>25201 CHAGRIN BLVD. #200<br>CLEVELAND, OH 44122-5683  |
| <b>Amount due or refund</b>                         | NOT APPLICABLE   |
| <b>Make check payable to</b>                        | NOT APPLICABLE   |
| <b>Mail tax return and check (if applicable) to</b> | NOT APPLICABLE   |
| <b>Return must be mailed on or before</b>           | NOT APPLICABLE   |
| <b>Special Instructions</b>                         | THIS RETURN HAS QUALIFIED FOR ELECTRONIC FILING. AFTER YOU HAVE REVIEWED THE RETURN FOR COMPLETENESS AND ACCURACY, PLEASE SIGN, DATE AND RETURN FORM 8879-TE TO OUR OFFICE. WE WILL TRANSMIT THE RETURN ELECTRONICALLY TO THE IRS AND NO FURTHER ACTION IS REQUIRED. RETURN FORM 8879-TE TO US BY NOVEMBER 17, 2025. |

Form **8879-TE**

# IRS E-file Signature Authorization for a Tax Exempt Entity

OMB No. 1545-0047

For calendar year 2024, or fiscal year beginning \_\_\_\_\_, 2024, and ending \_\_\_\_\_, 20\_\_

# 2024

Department of the Treasury  
Internal Revenue Service

**Do not send to the IRS. Keep for your records.**  
**Go to [www.irs.gov/Form8879TE](http://www.irs.gov/Form8879TE) for the latest information.**

Name of filer **CREUTZFELDT-JAKOB DISEASE FOUNDATION INC** EIN or SSN **65-0404623**

Name and title of officer or person subject to tax **DEBORAH YOBS  
PRESIDENT/EXECUTIVE DIRECTOR**

## Part I Type of Return and Return Information

Check the box for the return for which you are using this Form 8879-TE and enter the applicable amount, if any, from the return. Form 8038-CP and Form 5330 filers may enter dollars and cents. For all other forms, enter whole dollars only. If you check the box on line 1a, 2a, 3a, 4a, 5a, 6a, 7a, 8a, 9a, or 10a below, and the amount on that line for the return being filed with this form was blank, then leave line 1b, 2b, 3b, 4b, 5b, 6b, 7b, 8b, 9b, or 10b, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. Do not complete more than one line in Part I.

|   |   |                             |
|---|---|-----------------------------|
| <b>1a</b> Form 990 check here <input checked="" type="checkbox"/> | <b>b</b> Total revenue, if any (Form 990, Part VIII, column (A), line 12) .....     | <b>1b</b> <u>2,870,657.</u> |
| <b>2a</b> Form 990-EZ check here <input type="checkbox"/>         | <b>b</b> Total revenue, if any (Form 990-EZ, line 9) .....                          | <b>2b</b> _____             |
| <b>3a</b> Form 1120-POL check here <input type="checkbox"/>       | <b>b</b> Total tax (Form 1120-POL, line 22) .....                                   | <b>3b</b> _____             |
| <b>4a</b> Form 990-PF check here <input type="checkbox"/>         | <b>b</b> Tax based on investment income (Form 990-PF, Part V, line 5) .....         | <b>4b</b> _____             |
| <b>5a</b> Form 8868 check here <input type="checkbox"/>           | <b>b</b> Balance due (Form 8868, line 3c) .....                                     | <b>5b</b> _____             |
| <b>6a</b> Form 990-T check here <input type="checkbox"/>          | <b>b</b> Total tax (Form 990-T, Part III, line 4) .....                             | <b>6b</b> _____             |
| <b>7a</b> Form 4720 check here <input type="checkbox"/>           | <b>b</b> Total tax (Form 4720, Part III, line 1) .....                              | <b>7b</b> _____             |
| <b>8a</b> Form 5227 check here <input type="checkbox"/>           | <b>b</b> FMV of assets at end of tax year (Form 5227, Item D) .....                 | <b>8b</b> _____             |
| <b>9a</b> Form 5330 check here <input type="checkbox"/>           | <b>b</b> Tax due (Form 5330, Part II, line 19) .....                                | <b>9b</b> _____             |
| <b>10a</b> Form 8038-CP check here <input type="checkbox"/>       | <b>b</b> Amount of credit payment requested (Form 8038-CP, Part III, line 22) ..... | <b>10b</b> _____            |

## Part II Declaration and Signature Authorization of Officer or Person Subject to Tax

Under penalties of perjury, I declare that  I am an officer of the above entity or  I am a person subject to tax with respect to (name of entity) \_\_\_\_\_, (EIN) \_\_\_\_\_ and that I have examined a copy of the

2024 electronic return and accompanying schedules and statements, and, to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the electronic return and, if applicable, the consent to electronic funds withdrawal.

### PIN: check one box only

I authorize CIUNI & PANICHI, INC. to enter my PIN 04623  
ERO firm name Enter five numbers, but do not enter all zeros

as my signature on the tax year 2024 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer or person subject to tax with respect to the entity, I will enter my PIN as my signature on the tax year 2024 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Signature of officer or person subject to tax \_\_\_\_\_

Date \_\_\_\_\_

## Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN.

**34462325201**  
Do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2024 electronically filed return indicated above. I confirm that I am submitting this return in accordance with the requirements of Pub. 4163, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature \_\_\_\_\_ Date 10/23/25

**ERO Must Retain This Form - See Instructions**  
**Do Not Submit This Form to the IRS Unless Requested To Do So**

For Privacy Act and Paperwork Reduction Act Notice, see instructions.

Form **8879-TE** (2024)

**Application for Extension of Time To File an Exempt Organization  
Return or Excise Taxes Related to Employee Benefit Plans**

Department of the Treasury  
Internal Revenue Service

**File a separate application for each return.**  
**Go to [www.irs.gov/Form8868](http://www.irs.gov/Form8868) for the latest information.**

**Electronic filing (e-file).** You can electronically file Form 8868 to request up to a 6-month extension of time to file any of the forms listed below except for Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts. An extension request for Form 8870 must be sent to the IRS in a paper format (see instructions). For more details on the electronic filing of Form 8868, visit [www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits](http://www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits).

**Caution:** If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-TE and Form 8879-TE for payment instructions.

All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

**Part I - Identification**

|   |   |   |
|---|---|---|
| <b>Type or Print</b><br><br><small>File by the due date for filing your return. See instructions.</small> | Name of exempt organization, employer, or other filer, see instructions.<br><b>CREUTZFELDT-JAKOB DISEASE FOUNDATION INC</b> | Taxpayer identification number (TIN)<br><b>65-0404623</b> |
|   | Number, street, and room or suite no. If a P.O. box, see instructions.<br><b>3634 WEST MARKET STREET, 110</b>               |   |
|   | City, town or post office, state, and ZIP code. For a foreign address, see instructions.<br><b>AKRON, OH 44333</b>          |   |

Enter the Return Code for the return that this application is for (file a separate application for each return) ..... **01**

| Application Is For                       | Return Code | Application Is For                 | Return Code |
|--|-------------|------------------------------------|-------------|
| Form 990 or Form 990-EZ                  | 01          | Form 4720 (other than individual)  | 09          |
| Form 4720 (individual)                   | 03          | Form 5227                          | 10          |
| Form 990-PF                              | 04          | Form 6069                          | 11          |
| Form 990-T (sec. 401(a) or 408(a) trust) | 05          | Form 8870                          | 12          |
| Form 990-T (trust other than above)      | 06          | Form 5330 (individual)             | 13          |
| Form 990-T (corporation)                 | 07          | Form 5330 (other than individual)  | 14          |
| Form 1041-A                              | 08          | Form 990-T (governmental entities) | 15          |

• After you enter your Return Code, complete either Part II or Part III. Part III, including signature, is applicable only for an extension of time to file Form 5330.

• If this application is for an extension of time to file Form 5330, you must enter the following information.

Plan Name \_\_\_\_\_  
 Plan Number \_\_\_\_\_  
 Plan Year Ending (MM/DD/YYYY) \_\_\_\_\_

**Part II - Automatic Extension of Time To File for Exempt Organizations (see instructions)**

The books are in the care of **DEBORAH R YOBS**  
**3634 W MARKET STREET, SUITE 110 - AKRON, OH 44333**

Telephone No. **800-659-1991** Fax No. \_\_\_\_\_

- If the organization does not have an office or place of business in the United States, check this box
- If this is for a Group Return, enter the organization's four-digit Group Exemption Number (GEN) \_\_\_\_\_. If this is for the whole group, check this box . If it is for part of the group, check this box  and attach a list with the names and TINs of all members the extension is for.

**1** I request an automatic 6-month extension of time until **NOVEMBER 15**, 20 **25**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:  
 calendar year 20 **24** or  
 tax year beginning \_\_\_\_\_, 20 \_\_\_\_\_, and ending \_\_\_\_\_, 20 \_\_\_\_\_

**2** If the tax year entered in line 1 is for less than 12 months, check reason:  Initial return  Final return  
 Change in accounting period

|   |           |    |           |
|---|-----------|----|-----------|
| <b>3a</b> If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.   | <b>3a</b> | \$ | <b>0.</b> |
| <b>b</b> If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. | <b>3b</b> | \$ | <b>0.</b> |
| <b>c Balance due.</b> Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.              | <b>3c</b> | \$ | <b>0.</b> |

**For Privacy Act and Paperwork Reduction Act Notice, see instructions.**

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

Form 990

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

2024

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

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

A For the 2024 calendar year, or tax year beginning and ending
B Check if applicable:
C Name of organization: CREUTZFELDT-JAKOB DISEASE FOUNDATION INC
D Employer identification number: 65-0404623
E Telephone number: 800-659-1991
G Gross receipts \$: 5,676,716.
H(a) Is this a group return for subordinates?
H(b) Are all subordinates included?
I Tax-exempt status:
J Website: WWW.CJDFFOUNDATION.ORG
K Form of organization:
L Year of formation: 1993
M State of legal domicile: FL

Part I Summary
Table with columns: Activities & Governance, Revenue, Expenses, Net Assets or Fund Balances. Rows include mission statement, governance metrics, revenue breakdown, expenses, and asset/liability summary.

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.

Sign Here: Signature of officer DEBORAH YOBS, PRESIDENT/EXECUTIVE DIRECTOR
Date:
Paid Preparer Use Only: Preparer's name MICHAEL KLEIN, CPA; Signature MICHAEL KLEIN, CPA; Date 10/23/25; PTIN P00359504; Firm's name CIUNI & PANICHI, INC.; Firm's EIN 34-1322309; Firm's address 25201 CHAGRIN BLVD. #200 CLEVELAND, OH 44122-5683; Phone no. (216) 831-7171

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

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: CREUTZFELDT-JAKOB DISEASE (CJD) IS A RARE, RAPIDLY PROGRESSIVE NEURODEGENERATIVE DISEASE, ONE OF SEVERAL PRION DISEASES CAUSED BY PRION PROTEINS THAT MISFOLD IN THE BRAIN. THERE IS NO TREATMENT OR CURE AND THE DISEASE IS INVARIABLY FATAL. (CONTINUED ON SCHEDULE O)

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 [X] 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 [X] 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 \$ 503,902. including grants of \$ ) (Revenue \$ ) THE CJD FOUNDATION'S NATIONWIDE FAMILY SUPPORT PROGRAMS INCLUDE: HELPLINE SUPPORT AND RESOURCES, FAMILY CONFERENCE, FAMILY WORKSHOPS, MONTHLY VIRTUAL SUPPORT GROUPS, SPEAKER SERIES, BEREAVEMENT SUPPORT GROUPS, CAREGIVER SUPPORT GROUPS, AND REFERRALS TO THE TELENEUROLOGY ASSESSMENT PROGRAM FOR CJD (TAPCJD). THE CJD FOUNDATION PROVIDES FUNDING AND REFERRALS FOR TAPCJD AND OFFERS GUIDANCE, EDUCATION, AND SUPPORT TO FAMILIES AFFECTED BY PRION DISEASE, WHILE COLLECTING NATURAL HISTORY DATA THAT CAN BE USED FOR A VARIETY OF RESEARCH PURPOSES.

HELPLINE SUPPORT: THE CJD FOUNDATION RESPONDED TO 2,563 CALLS AND EMAILS IN 2024, PROVIDING INFORMATION AND REFERRALS AND RESPONDING TO QUESTIONS AND CONCERNS FROM FAMILY MEMBERS, (CONTINUED ON SCHEDULE O)

4b (Code: ) (Expenses \$ 1,007,819. including grants of \$ 702,920.) (Revenue \$ 0.) IN 2024, THE CJD FOUNDATION AWARDED \$702,920 IN GRANTS TO 8 RESEARCHERS SELECTED BY OUR SCIENTIFIC ADVISORY COMMITTEE, WHICH COMPRISES INTERNATIONAL PRION DISEASE EXPERTS. 50 RESEARCHERS WORLDWIDE APPLIED. GRANT RECIPIENTS PRESENT THEIR RESEARCH AT THE CJD FOUNDATION'S ANNUAL FAMILY CONFERENCE. THE CJD FOUNDATION HAS AWARDED MORE THAN 94 RESEARCH GRANTS SINCE 2006, FUNDING A NUMBER OF GROUNDBREAKING PROJECTS THAT HAVE LED TO IMPORTANT NEW DISCOVERIES. FUNDING COMES FROM FAMILY MEMORIAL RESEARCH GRANTS AND FROM THE FUNDRAISING ACTIVITIES OF THE CJD FOUNDATION.

4c (Code: ) (Expenses \$ 41,571. including grants of \$ ) (Revenue \$ ) THE CJD FOUNDATION HOSTS GRAND ROUND PRESENTATIONS, INFECTION CONTROL SEMINARS, AND FUNERAL EDUCATION AROUND THE COUNTRY, AT NO CHARGE. OUR MEDICAL EDUCATION PROGRAMS ARE INSTRUCTED BY PRION DISEASE EXPERTS. IN 2024, WE PROVIDED MEDICAL EDUCATION:

- MEDICAL EDUCATION NEUROLOGY GRAND ROUNDS WERE HELD IN: - TEXAS AT DSHS, WHICH INCLUDES STAFF FROM DSHS, HEALTH AND HUMAN SERVICES COMMISSION, LOCAL HEALTH DEPARTMENTS, LOCAL MENTAL HEALTH CENTERS, HOSPITALS, INSTITUTIONS OF HIGHER EDUCATION, AND OTHERS THROUGHOUT TEXAS. - IMED/SALT LAKE VALLEY NEUROLOGY DEPARTMENT (CONTINUED ON SCHEDULE O)

4d Other program services (Describe on Schedule O.) (Expenses \$ 46,831. including grants of \$ ) (Revenue \$ )

4e Total program service expenses 1,600,123.

Part IV Checklist of Required Schedules

Table with 3 columns: Question, Yes, No. Rows 1-21 detailing various organizational requirements and their status.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question, Yes, No. Rows 22-38. Includes questions about grants, compensation, tax-exempt bonds, excess benefit transactions, and noncash contributions.

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

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

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

Table with columns for question number, question text, and Yes/No columns. Includes questions 2a through 17 regarding employee reporting, tax returns, unrelated business income, foreign accounts, prohibited transactions, and charitable contributions.



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

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year (19); 1b Enter the number of voting members included on line 1a, above, who are independent (19); 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? (X); 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? (X); 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? (X); 5 Did the organization become aware during the year of a significant diversion of the organization's assets? (X); 6 Did the organization have members or stockholders? (X); 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? (X); 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? (X); 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: a The governing body? (X); b Each committee with authority to act on behalf of the governing body? (X); 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 on Schedule O (X).

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? (X); 10b 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?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? (X); 11b 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 (X); 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? (X); 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done (X); 13 Did the organization have a written whistleblower policy? (X); 14 Did the organization have a written document retention and destruction policy? (X); 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? a The organization's CEO, Executive Director, or top management official (X); b Other officers or key employees of the organization (X); If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.; 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? (X); 16b 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?

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed CA, CO, CT, DE, FL, IL, KS, MA, MD, NJ, NY, OH
18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. [X] Own website [ ] Another's website [X] Upon request [ ] Other (explain on Schedule O)
19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records
DEBORAH R YOBS - 800-659-1991
3634 W MARKET STREET, SUITE 110, AKRON, OH 44333

**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, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See 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)<br>Name and title                                 | (B)<br>Average hours per week (list any hours for related organizations below line) | (C)<br>Position (do not check more than one box, unless person is both an officer and a director/trustee) |                       |         |              |                              |        | (D)<br>Reportable compensation from the organization (W-2/1099-MISC/1099-NEC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|---|---|---|-----------------------|---------|--------------|------------------------------|--------|---|--|---|
|   |   | Individual trustee or director  | Institutional trustee | Officer | Key employee | Highest compensated employee | Former |   |  |   |
| (1) DEBORAH YOBS<br>PRESIDENT/EXECUTIVE DIRECTOR      | 40.00   |   |                       | X       |              |                              |        | 111,457.  | 0.   | 0.  |
| (2) BRIAN APPLEBY<br>BOARD MEMBER                     | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (3) TREVOR BAIERL<br>BOARD MEMBER (THROUGH 2/28/24)   | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (4) MATT COLLINS<br>BOARD MEMBER                      | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (5) PAMELA FEAR<br>BOARD MEMBER                       | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (6) LAVONNE HALL<br>BOARD MEMBER (THROUGH 2/7/24)     | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (7) CLARENCE HUNTER<br>BOARD MEMBER                   | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (8) AMANDA BAXLEY KALINSKY<br>BOARD MEMBER            | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (9) JANINE KOCK<br>BOARD MEMBER                       | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (10) PATRICIA MCGILL<br>TREASURER                     | 2.00  | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
| (11) KIRSTEN MCGINNIS<br>SECRETARY                    | 2.00  | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
| (12) BRENDA MEANEY<br>BOARD MEMBER                    | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (13) DAVE MORRIS<br>BOARD MEMBER                      | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (14) FRANK MYERS<br>BOARD MEMBER                      | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (15) MOLLY NOCERINO<br>BOARD MEMBER (THROUGH 4/30/24) | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (16) JOE POHL<br>BOARD MEMBER                         | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (17) MARK ROBERTS<br>BOARD MEMBER                     | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |

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

| (A)<br>Name and title  | (B)<br>Average hours per week (list any hours for related organizations below line) | (C)<br>Position (do not check more than one box, unless person is both an officer and a director/trustee) |                       |         |              |                              |        | (D)<br>Reportable compensation from the organization (W-2/1099-MISC/1099-NEC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|--|---|---|-----------------------|---------|--------------|------------------------------|--------|---|--|---|
|  |   | Individual trustee or director  | Institutional trustee | Officer | Key employee | Highest compensated employee | Former |   |  |   |
| (18) JACOB SCHWISTER<br>BOARD MEMBER                                 | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (19) TIM SCHWISTER<br>BOARD MEMBER                                   | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (20) NANCY SWEELY<br>BOARD MEMBER                                    | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (21) MARIA THACKER-GOETHE<br>BOARD MEMBER                            | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (22) MICHAEL VITANZA<br>BOARD MEMBER (THROUGH 7/10/24)               | 2.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (23) STUART YAFFA<br>CHAIR   | 2.00  | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
|  |   |   |                       |         |              |                              |        |   |  |   |
|  |   |   |                       |         |              |                              |        |   |  |   |
|  |   |   |                       |         |              |                              |        |   |  |   |
|  |   |   |                       |         |              |                              |        |   |  |   |
| <b>1b Subtotal</b> .....   |   |   |                       |         |              |                              |        | 111,457.  | 0.   | 0.  |
| <b>c Total from continuation sheets to Part VII, Section A</b> ..... |   |   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| <b>d Total (add lines 1b and 1c)</b> .....                           |   |   |                       |         |              |                              |        | 111,457.  | 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 1

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

**Section B. Independent Contractors**

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

| (A)<br>Name and business address | (B)<br>Description of services | (C)<br>Compensation |
|----------------------------------|--------------------------------|---------------------|
| NONE                             |                                |                     |
|                                  |                                |                     |
|                                  |                                |                     |
|                                  |                                |                     |
|                                  |                                |                     |

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

**Part VIII Statement of Revenue**

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

|  |   |                              | (A)                  | (B)                                | (C)                        | (D)  |  |
|--|---|------------------------------|----------------------|------------------------------------|----------------------------|--|--|
|  |   |                              | Total revenue        | Related or exempt function revenue | Unrelated business revenue | Revenue excluded from tax under sections 512 - 514 |  |
| <b>Contributions, Gifts, Grants and Other Similar Amounts</b>  | <b>1 a</b> Federated campaigns  | <b>1a</b>                    |                      |                                    |                            |  |  |
|  | <b>b</b> Membership dues  | <b>1b</b>                    |                      |                                    |                            |  |  |
|  | <b>c</b> Fundraising events   | <b>1c</b>                    | 743,496.             |                                    |                            |  |  |
|  | <b>d</b> Related organizations  | <b>1d</b>                    |                      |                                    |                            |  |  |
|  | <b>e</b> Government grants (contributions)  | <b>1e</b>                    | 75,325.              |                                    |                            |  |  |
|  | <b>f</b> All other contributions, gifts, grants, and similar amounts not included above | <b>1f</b>                    | 1,644,892.           |                                    |                            |  |  |
|  | <b>g</b> Noncash contributions included in lines 1a-1f                                  | <b>1g</b>                    | \$                   |                                    |                            |  |  |
|  | <b>h Total.</b> Add lines 1a-1f   |                              |                      | 2,463,713.                         |                            |  |  |
|  | <b>Program Service Revenue</b>  | <b>2 a</b> CONFERENCE INCOME | <b>Business Code</b> | 541900                             | 101,200.                   | 101,200.   |  |
| <b>b</b>   |   |                              |                      |                                    |                            |  |  |
| <b>c</b>   |   |                              |                      |                                    |                            |  |  |
| <b>d</b>   |   |                              |                      |                                    |                            |  |  |
| <b>e</b>   |   |                              |                      |                                    |                            |  |  |
| <b>f</b> All other program service revenue   |   |                              |                      |                                    |                            |  |  |
| <b>g Total.</b> Add lines 2a-2f  |   |                              |                      | 101,200.                           |                            |  |  |
| <b>Other Revenue</b>   | <b>3</b> Investment income (including dividends, interest, and other similar amounts)   |                              |                      | 327,506.                           | 327,506.                   |  |  |
|  | <b>4</b> Income from investment of tax-exempt bond proceeds                             |                              |                      |                                    |                            |  |  |
|  | <b>5</b> Royalties  |                              |                      |                                    |                            |  |  |
|  | <b>6 a</b> Gross rents  | <b>6a</b>                    | (i) Real             |                                    |                            |  |  |
|  |   |                              | (ii) Personal        |                                    |                            |  |  |
|  |   |                              |                      |                                    |                            |  |  |
|  | <b>b</b> Less: rental expenses  | <b>6b</b>                    |                      |                                    |                            |  |  |
|  | <b>c</b> Rental income or (loss)  | <b>6c</b>                    |                      |                                    |                            |  |  |
|  | <b>d</b> Net rental income or (loss)  |                              |                      |                                    |                            |  |  |
|  | <b>7 a</b> Gross amount from sales of assets other than inventory                       | <b>7a</b>                    | (i) Securities       | 2,767,238.                         |                            |  |  |
|  |   |                              | (ii) Other           |                                    |                            |  |  |
|  |   |                              |                      |                                    |                            |  |  |
|  | <b>b</b> Less: cost or other basis and sales expenses                                   | <b>7b</b>                    | 2,753,276.           |                                    |                            |  |  |
|  | <b>c</b> Gain or (loss)   | <b>7c</b>                    | 13,962.              |                                    |                            |  |  |
|  | <b>d</b> Net gain or (loss)   |                              |                      | 13,962.                            |                            | 13,962.  |  |
| <b>8 a</b> Gross income from fundraising events (not including \$ 743,496. of contributions reported on line 1c). See Part IV, line 18 | <b>8a</b>   |                              | 14,359.              |                                    |                            |  |  |
|  |   |                              | 52,783.              |                                    |                            |  |  |
|  |   |                              |                      |                                    |                            |  |  |
| <b>b</b> Less: direct expenses   | <b>8b</b>   |                              |                      |                                    |                            |  |  |
| <b>c</b> Net income or (loss) from fundraising events  |   |                              | -38,424.             |                                    | -38,424.                   |  |  |
| <b>9 a</b> Gross income from gaming activities. See Part IV, line 19   | <b>9a</b>   |                              |                      |                                    |                            |  |  |
|  |   |                              |                      |                                    |                            |  |  |
| <b>b</b> Less: direct expenses   | <b>9b</b>   |                              |                      |                                    |                            |  |  |
| <b>c</b> Net income or (loss) from gaming activities   |   |                              |                      |                                    |                            |  |  |
| <b>10 a</b> Gross sales of inventory, less returns and allowances  | <b>10a</b>  |                              |                      |                                    |                            |  |  |
|  |   |                              |                      |                                    |                            |  |  |
|  |   |                              |                      |                                    |                            |  |  |
| <b>b</b> Less: cost of goods sold  | <b>10b</b>  |                              |                      |                                    |                            |  |  |
| <b>c</b> Net income or (loss) from sales of inventory  |   |                              |                      |                                    |                            |  |  |
| <b>Miscellaneous Revenue</b>   | <b>11 a</b> MISCELLANEOUS   | <b>Business Code</b>         | 541900               | 2,700.                             | 2,700.                     |  |  |
|  | <b>b</b>  |                              |                      |                                    |                            |  |  |
|  | <b>c</b>  |                              |                      |                                    |                            |  |  |
|  | <b>d</b> All other revenue  |                              |                      |                                    |                            |  |  |
|  | <b>e Total.</b> Add lines 11a-11d   |                              |                      | 2,700.                             |                            |  |  |
| <b>12 Total revenue.</b> See instructions  |   |                              | 2,870,657.           | 431,406.                           | 0.                         | -24,462.   |  |

**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)<br>Total expenses | (B)<br>Program service expenses | (C)<br>Management and general expenses | (D)<br>Fundraising expenses |
|--|-----------------------|---------------------------------|--|-----------------------------|
| 1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21   | 200,000.              | 200,000.                        |  |                             |
| 2 Grants and other assistance to domestic individuals. See Part IV, line 22  |                       |                                 |  |                             |
| 3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16   | 502,920.              | 502,920.                        |  |                             |
| 4 Benefits paid to or for members  |                       |                                 |  |                             |
| 5 Compensation of current officers, directors, trustees, and key employees   | 111,457.              | 87,128.                         | 15,302.                                | 9,027.                      |
| 6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)   |                       |                                 |  |                             |
| 7 Other salaries and wages   | 252,770.              | 197,594.                        | 34,702.                                | 20,474.                     |
| 8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)   |                       |                                 |  |                             |
| 9 Other employee benefits  | 3,230.                |                                 | 3,230.                                 |                             |
| 10 Payroll taxes   | 30,035.               | 23,479.                         | 4,123.                                 | 2,433.                      |
| 11 Fees for services (nonemployees):   |                       |                                 |  |                             |
| a Management   |                       |                                 |  |                             |
| b Legal  |                       |                                 |  |                             |
| c Accounting   | 16,105.               |                                 | 16,105.                                |                             |
| d Lobbying   |                       |                                 |  |                             |
| e Professional fundraising services. See Part IV, line 17  |                       |                                 |  |                             |
| f Investment management fees   | 12,927.               |                                 | 12,927.                                |                             |
| g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)   | 109,052.              | 62,415.                         | 31,122.                                | 15,515.                     |
| 12 Advertising and promotion   |                       |                                 |  |                             |
| 13 Office expenses   | 22,632.               | 12,638.                         | 9,583.                                 | 411.                        |
| 14 Information technology  |                       |                                 |  |                             |
| 15 Royalties   |                       |                                 |  |                             |
| 16 Occupancy   | 25,759.               | 17,898.                         | 6,007.                                 | 1,854.                      |
| 17 Travel  |                       |                                 |  |                             |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials  |                       |                                 |  |                             |
| 19 Conferences, conventions, and meetings  | 198,620.              | 198,620.                        |  |                             |
| 20 Interest  |                       |                                 |  |                             |
| 21 Payments to affiliates  |                       |                                 |  |                             |
| 22 Depreciation, depletion, and amortization   | 18,918.               |                                 | 18,918.                                |                             |
| 23 Insurance   | 8,914.                |                                 | 8,914.                                 |                             |
| 24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.)   |                       |                                 |  |                             |
| a <b>PROGRAM EXPENSE</b>   | 297,431.              | 297,431.                        |  |                             |
| b <b>DONATION COLLECTION FEE</b>   | 16,005.               |                                 | 3,043.                                 | 12,962.                     |
| c <b>FAMILY FUNDRAISING</b>  | 11,332.               |                                 |  | 11,332.                     |
| d <b>ANNUAL FUND EXPENSE</b>   | 8,817.                |                                 |  | 8,817.                      |
| e All other expenses   | 19,026.               |                                 | 12,850.                                | 6,176.                      |
| <b>25 Total functional expenses.</b> Add lines 1 through 24e   | <b>1,865,950.</b>     | <b>1,600,123.</b>               | <b>176,826.</b>                        | <b>89,001.</b>              |
| <b>26 Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) |                       |                                 |  |                             |

**Part X Balance Sheet**

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

|   |  | (A)<br>Beginning of year |            | (B)<br>End of year |
|---|--|--------------------------|------------|--------------------|
| <b>Assets</b>   | <b>1</b> Cash - non-interest-bearing .....   | 251.                     | <b>1</b>   | 300.               |
|   | <b>2</b> Savings and temporary cash investments .....  | 442,999.                 | <b>2</b>   | 298,503.           |
|   | <b>3</b> Pledges and grants receivable, net .....  | 35,054.                  | <b>3</b>   | 358,775.           |
|   | <b>4</b> Accounts receivable, net .....  | 20,067.                  | <b>4</b>   |                    |
|   | <b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons ..... |                          | <b>5</b>   |                    |
|   | <b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) .....   |                          | <b>6</b>   |                    |
|   | <b>7</b> Notes and loans receivable, net .....   |                          | <b>7</b>   |                    |
|   | <b>8</b> Inventories for sale or use .....   | 7,583.                   | <b>8</b>   | 12,613.            |
|   | <b>9</b> Prepaid expenses and deferred charges .....   | 18,621.                  | <b>9</b>   | 123,997.           |
|   | <b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....   | <b>10a</b> 77,763.       |            |                    |
|   | <b>b</b> Less: accumulated depreciation .....  | <b>10b</b> 45,637.       | 38,069.    | <b>10c</b> 32,126. |
|   | <b>11</b> Investments - publicly traded securities .....   | 7,531,936.               | <b>11</b>  | 8,352,199.         |
|   | <b>12</b> Investments - other securities. See Part IV, line 11 .....   |                          | <b>12</b>  |                    |
|   | <b>13</b> Investments - program-related. See Part IV, line 11 .....  |                          | <b>13</b>  |                    |
|   | <b>14</b> Intangible assets .....  | 41,667.                  | <b>14</b>  |                    |
|   | <b>15</b> Other assets. See Part IV, line 11 .....   | 1,289.                   | <b>15</b>  | 10,307.            |
| <b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) ..... | 8,137,536.   | <b>16</b>                | 9,188,820. |                    |
| <b>Liabilities</b>  | <b>17</b> Accounts payable and accrued expenses .....  | 18,694.                  | <b>17</b>  | 38,085.            |
|   | <b>18</b> Grants payable .....   | 77,235.                  | <b>18</b>  |                    |
|   | <b>19</b> Deferred revenue .....   |                          | <b>19</b>  |                    |
|   | <b>20</b> Tax-exempt bond liabilities .....  |                          | <b>20</b>  |                    |
|   | <b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D .....  |                          | <b>21</b>  |                    |
|   | <b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....     |                          | <b>22</b>  |                    |
|   | <b>23</b> Secured mortgages and notes payable to unrelated third parties .....   |                          | <b>23</b>  |                    |
|   | <b>24</b> Unsecured notes and loans payable to unrelated third parties .....   | 32,028.                  | <b>24</b>  |                    |
|   | <b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24), Complete Part X of Schedule D .....  | 0.                       | <b>25</b>  | 9,633.             |
|   | <b>26 Total liabilities.</b> Add lines 17 through 25 .....   | 127,957.                 | <b>26</b>  | 47,718.            |
| <b>Net Assets or Fund Balances</b>  | <b>Organizations that follow FASB ASC 958, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27, 28, 32, and 33.</b>  |                          |            |                    |
|   | <b>27</b> Net assets without donor restrictions .....  | 5,711,402.               | <b>27</b>  | 6,797,504.         |
|   | <b>28</b> Net assets with donor restrictions .....   | 2,298,177.               | <b>28</b>  | 2,343,598.         |
|   | <b>Organizations that do not follow FASB ASC 958, check here</b> <input type="checkbox"/> <b>and complete lines 29 through 33.</b>   |                          |            |                    |
|   | <b>29</b> Capital stock or trust principal, or current funds .....   |                          | <b>29</b>  |                    |
|   | <b>30</b> Paid-in or capital surplus, or land, building, or equipment fund .....   |                          | <b>30</b>  |                    |
|   | <b>31</b> Retained earnings, endowment, accumulated income, or other funds .....   |                          | <b>31</b>  |                    |
| <b>32</b> Total net assets or fund balances .....                         | 8,009,579.   | <b>32</b>                | 9,141,102. |                    |
| <b>33</b> Total liabilities and net assets/fund balances .....            | 8,137,536.   | <b>33</b>                | 9,188,820. |                    |

**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  | 2,870,657. |
| 2  | Total expenses (must equal Part IX, column (A), line 25)   | 2  | 1,865,950. |
| 3  | Revenue less expenses. Subtract line 2 from line 1   | 3  | 1,004,707. |
| 4  | Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))                      | 4  | 8,009,579. |
| 5  | Net unrealized gains (losses) on investments   | 5  | 126,816.   |
| 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 on Schedule O)   | 9  | 0.         |
| 10 | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B)) | 10 | 9,141,102. |

**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 type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____<br>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? _____<br>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:<br><input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis |     | X  |
| b  | Were the organization's financial statements audited by an independent accountant? _____<br>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:<br><input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis                | X   |    |
| c  | 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? _____<br>If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.   | X   |    |
| 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? _____   |     | X  |
| b  | If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits _____  |     |    |

Form 990 (2024)

**SCHEDULE A**  
**(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

OMB No. 1545-0047

**2024**

Open to Public Inspection

Name of the organization **CREUTZFELDT-JAKOB DISEASE FOUNDATION INC** Employer identification number **65-0404623**

**Part I Reason for Public Charity Status.** (All organizations must complete this part.) See instructions.

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

- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**
- 2  A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990).)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 9  An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: \_\_\_\_\_
- 10  An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box 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 |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
|                                    |          |   |   |    |   |   |
| <b>Total</b>                       |          |   |   |    |   |   |



**Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)**

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

| Calendar year (or fiscal year beginning in)  | (a) 2020   | (b) 2021   | (c) 2022   | (d) 2023   | (e) 2024   | (f) Total   |
|--|------------|------------|------------|------------|------------|-------------|
| <b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....  | 1,732,905. | 2,482,682. | 2,735,803. | 2,770,443. | 2,463,713. | 12,185,546. |
| <b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....   |            |            |            |            |            |             |
| <b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....   |            |            |            |            |            |             |
| <b>4 Total.</b> Add lines 1 through 3 .....  | 1,732,905. | 2,482,682. | 2,735,803. | 2,770,443. | 2,463,713. | 12,185,546. |
| <b>5</b> 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) ..... |            |            |            |            |            | 1,198,567.  |
| <b>6 Public support.</b> Subtract line 5 from line 4.  |            |            |            |            |            | 10,986,979. |

**Section B. Total Support**

| Calendar year (or fiscal year beginning in)  | (a) 2020   | (b) 2021   | (c) 2022   | (d) 2023   | (e) 2024   | (f) Total   |
|--|------------|------------|------------|------------|------------|-------------|
| <b>7</b> Amounts from line 4 .....   | 1,732,905. | 2,482,682. | 2,735,803. | 2,770,443. | 2,463,713. | 12,185,546. |
| <b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources ..... | 22,028.    | 37,997.    | 83,547.    | 245,716.   | 327,506.   | 716,794.    |
| <b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on .....                              | 165.       | 10,270.    | 88,001.    | 46,635.    | 0.         | 145,071.    |
| <b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....                                |            |            |            |            | 2,700.     | 2,700.      |
| <b>11 Total support.</b> Add lines 7 through 10  |            |            |            |            |            | 13,050,111. |
| <b>12</b> Gross receipts from related activities, etc. (see instructions) .....  |            |            |            |            | 12         | 166,098.    |

**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**

|   |           |         |
|---|-----------|---------|
| <b>14</b> Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f)) ..... | <b>14</b> | 84.19 % |
| <b>15</b> Public support percentage from 2023 Schedule A, Part II, line 14 .....                        | <b>15</b> | 87.28 % |

**16a 33 1/3% support test - 2024.** 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 - 2023.** 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 - 2024.** 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 - 2023.** 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

**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) 2020 | (b) 2021 | (c) 2022 | (d) 2023 | (e) 2024 | (f) Total |
|---|----------|----------|----------|----------|----------|-----------|
| <b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....   |          |          |          |          |          |           |
| <b>2</b> Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose ..... |          |          |          |          |          |           |
| <b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 .....   |          |          |          |          |          |           |
| <b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....  |          |          |          |          |          |           |
| <b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....  |          |          |          |          |          |           |
| <b>6 Total.</b> Add lines 1 through 5 .....   |          |          |          |          |          |           |
| <b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons .....  |          |          |          |          |          |           |
| <b>b</b> Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year .....           |          |          |          |          |          |           |
| <b>c</b> Add lines 7a and 7b .....  |          |          |          |          |          |           |
| <b>8 Public support.</b> (Subtract line 7c from line 6.)  |          |          |          |          |          |           |

**Section B. Total Support**

| Calendar year (or fiscal year beginning in)  | (a) 2020 | (b) 2021 | (c) 2022 | (d) 2023 | (e) 2024 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| <b>9</b> Amounts from line 6 .....   |          |          |          |          |          |           |
| <b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources ..... |          |          |          |          |          |           |
| <b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....                           |          |          |          |          |          |           |
| <b>c</b> Add lines 10a and 10b .....   |          |          |          |          |          |           |
| <b>11</b> Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on .....      |          |          |          |          |          |           |
| <b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....                                  |          |          |          |          |          |           |
| <b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.)   |          |          |          |          |          |           |

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

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

|   |           |   |
|---|-----------|---|
| <b>15</b> Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f)) ..... | <b>15</b> | % |
| <b>16</b> Public support percentage from 2023 Schedule A, Part III, line 15 .....                       | <b>16</b> | % |

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

|  |           |   |
|--|-----------|---|
| <b>17</b> Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f)) ..... | <b>17</b> | % |
| <b>18</b> Investment income percentage from 2023 Schedule A, Part III, line 17 .....                         | <b>18</b> | % |

**19a 33 1/3% support tests - 2024.** 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 - 2023.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

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

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

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

**Part IV Supporting Organizations** (continued)

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

**Section B. Type I Supporting Organizations**

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

**Section C. Type II Supporting Organizations**

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

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

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

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

|   |     |    |
|---|-----|----|
| <b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).  |     |    |
| <b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.  |     |    |
| <b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.   |     |    |
| <b>c</b> <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).   |     |    |
| <b>2</b> Activities Test. Answer lines 2a and 2b below.   |     |    |
| <b>a</b> Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i> | Yes | No |
| <b>b</b> Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>  |     |    |
| <b>3</b> Parent of Supported Organizations. Answer lines 3a and 3b below.   |     |    |
| <b>a</b> Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No," provide details in Part VI.</i>  |     |    |
| <b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>   |     |    |

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

| Section C - Distributable Amount |   |   | Current Year |
|----------------------------------|---|---|--------------|
| 1                                | Adjusted net income for prior year (from Section A, line 8, column A)   | 1 |              |
| 2                                | Enter 0.85 of line 1.   | 2 |              |
| 3                                | Minimum asset amount for prior year (from Section B, line 8, column A)  | 3 |              |
| 4                                | Enter greater of line 2 or line 3.  | 4 |              |
| 5                                | Income tax imposed in prior year  | 5 |              |
| 6                                | <b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).   | 6 |              |
| 7                                | <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions). |   |              |

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

| <b>Section D - Distributions</b> |   | <b>Current Year</b> |
|----------------------------------|---|---------------------|
| <b>1</b>                         | Amounts paid to supported organizations to accomplish exempt purposes   | <b>1</b>            |
| <b>2</b>                         | Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity               | <b>2</b>            |
| <b>3</b>                         | Administrative expenses paid to accomplish exempt purposes of supported organizations   | <b>3</b>            |
| <b>4</b>                         | Amounts paid to acquire exempt-use assets   | <b>4</b>            |
| <b>5</b>                         | Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i> )  | <b>5</b>            |
| <b>6</b>                         | Other distributions (describe in <b>Part VI</b> ). See instructions.  | <b>6</b>            |
| <b>7</b>                         | <b>Total annual distributions.</b> Add lines 1 through 6.   | <b>7</b>            |
| <b>8</b>                         | Distributions to attentive supported organizations to which the organization is responsive ( <i>provide details in Part VI</i> ). See instructions. | <b>8</b>            |
| <b>9</b>                         | Distributable amount for 2024 from Section C, line 6  | <b>9</b>            |
| <b>10</b>                        | Line 8 amount divided by line 9 amount  | <b>10</b>           |

| <b>Section E - Distribution Allocations</b> (see instructions)   | <b>(i)<br/>Excess Distributions</b> | <b>(ii)<br/>Underdistributions<br/>Pre-2024</b> | <b>(iii)<br/>Distributable<br/>Amount for 2024</b> |
|--|-------------------------------------|---|--|
| <b>1</b> Distributable amount for 2024 from Section C, line 6  |                                     |   |  |
| <b>2</b> Underdistributions, if any, for years prior to 2024 (reasonable cause required - <i>explain in Part VI</i> ). See instructions.   |                                     |   |  |
| <b>3</b> Excess distributions carryover, if any, to 2024   |                                     |   |  |
| <b>a</b> From 2019   |                                     |   |  |
| <b>b</b> From 2020   |                                     |   |  |
| <b>c</b> From 2021   |                                     |   |  |
| <b>d</b> From 2022   |                                     |   |  |
| <b>e</b> From 2023   |                                     |   |  |
| <b>f</b> <b>Total</b> of lines 3a through 3e   |                                     |   |  |
| <b>g</b> Applied to under distributions of prior years   |                                     |   |  |
| <b>h</b> Applied to 2024 distributable amount  |                                     |   |  |
| <b>i</b> Carryover from 2019 not applied (see instructions)  |                                     |   |  |
| <b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.  |                                     |   |  |
| <b>4</b> Distributions for 2024 from Section D, line 7: \$   |                                     |   |  |
| <b>a</b> Applied to underdistributions of prior years  |                                     |   |  |
| <b>b</b> Applied to 2024 distributable amount  |                                     |   |  |
| <b>c</b> Remainder. Subtract lines 4a and 4b from line 4.  |                                     |   |  |
| <b>5</b> Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions. |                                     |   |  |
| <b>6</b> Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.                        |                                     |   |  |
| <b>7</b> <b>Excess distributions carryover to 2025.</b> Add lines 3j and 4c.   |                                     |   |  |
| <b>8</b> Breakdown of line 7:  |                                     |   |  |
| <b>a</b> Excess from 2020  |                                     |   |  |
| <b>b</b> Excess from 2021  |                                     |   |  |
| <b>c</b> Excess from 2022  |                                     |   |  |
| <b>d</b> Excess from 2023  |                                     |   |  |
| <b>e</b> Excess from 2024  |                                     |   |  |



**SCHEDULE C**  
**(Form 990)**

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2024**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

**For Organizations Exempt From Income Tax Under Section 501(c) and Section 527**  
**Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.**  
**Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.**

**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 I-B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and I-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 organization<br><b>CREUTZFELDT-JAKOB DISEASE FOUNDATION INC</b> | Employer identification number (EIN)<br><b>65-0404623</b> |
|---|---|

**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.
- 2 Political campaign activity expenditures ..... \$ \_\_\_\_\_
- 3 Volunteer hours for political campaign activities ..... \_\_\_\_\_

**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 EINs 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-. |
|----------|-------------|---------|---|--|
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |
|          |             |         |   |  |

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

Schedule C (Form 990) 2024



**Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under 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<br>(The term "expenditures" means amounts paid or incurred.)   |  | (a) Filing organization's totals | (b) Affiliated group totals                              |
|--|--|----------------------------------|--|
| <b>1a</b> Total lobbying expenditures to influence public opinion (grassroots lobbying) .....  |  |                                  |  |
| <b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying) .....   |  |                                  |  |
| <b>c</b> Total lobbying expenditures (add lines 1a and 1b) .....   |  |                                  |  |
| <b>d</b> Other exempt purpose expenditures .....   |  | 1,865,950.                       |  |
| <b>e</b> Total exempt purpose expenditures (add lines 1c and 1d) .....   |  | 1,865,950.                       |  |
| <b>f</b> Lobbying nontaxable amount. Enter the amount from the following table in both columns.  |  | 243,298.                         |  |
| <b>IF the amount on line 1e, column (a) or (b), is:</b>  | <b>THEN the lobbying nontaxable amount is:</b>     |                                  |  |
| 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.                                       |                                  |  |
| <b>g</b> Grassroots nontaxable amount (enter 25% of line 1f) .....   |  | 60,825.                          |  |
| <b>h</b> Subtract line 1g from line 1a. If zero or less, enter -0- .....   |  | 0.                               |  |
| <b>i</b> Subtract line 1f from line 1c. If zero or less, enter -0- .....   |  | 0.                               |  |
| <b>j</b> 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<br>(or fiscal year beginning in)                      | (a) 2021 | (b) 2022 | (c) 2023 | (d) 2024 | (e) Total  |
| <b>2a</b> Lobbying nontaxable amount                                | 186,581. | 205,311. | 239,784. | 243,298. | 874,974.   |
| <b>b</b> Lobbying ceiling amount<br>(150% of line 2a, column(e))    |          |          |          |          | 1,312,461. |
| <b>c</b> Total lobbying expenditures                                | 19,559.  | 0.       | 0.       |          | 19,559.    |
| <b>d</b> Grassroots nontaxable amount                               | 46,645.  | 51,328.  | 59,946.  | 60,825.  | 218,744.   |
| <b>e</b> Grassroots ceiling amount<br>(150% of line 2d, column (e)) |          |          |          |          | 328,116.   |
| <b>f</b> Grassroots lobbying expenditures                           |          |          |          |          |            |

Schedule C (Form 990) 2024

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)).

Table with 4 columns: Description, (a) Yes, (a) No, (b) Amount. Rows include questions about lobbying activities like influencing legislation, volunteers, paid staff, media, mailings, publications, grants, direct contact, rallies, and other activities.

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

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

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."

Table with 3 columns: Question, Yes, No. Rows include: 1. Dues, assessments, and similar amounts from members. 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, b. Carryover from last year, c. Total. 3. Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues. 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 expenditures next year? 5. Taxable amount of lobbying and political expenditures. See instructions.

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.

Multiple horizontal lines provided for entering supplemental information.

**SCHEDULE D**  
**(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

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

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

OMB No. 1545-0047

Open to Public  
Inspection

Name of the organization **CREUTZFELDT-JAKOB DISEASE FOUNDATION INC** Employer identification number **65-0404623**

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

|   | (a) Donor advised funds | (b) Funds and other accounts                             |
|---|-------------------------|--|
| 1 Total number at end of year .....   |                         |  |
| 2 Aggregate value of contributions to (during year) .....   |                         |  |
| 3 Aggregate value of grants from (during year) .....  |                         |  |
| 4 Aggregate value at end of year .....  |                         |  |
| 5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? .....  |                         | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ..... |                         | <input type="checkbox"/> Yes <input type="checkbox"/> No |

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

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

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

|  | Held at the End of the Tax Year |
|--|---------------------------------|
| a Total number of conservation easements .....   | 2a                              |
| b Total acreage restricted by conservation easements .....   | 2b                              |
| c Number of conservation easements on a certified historic structure included on line 2a .....   | 2c                              |
| d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register ..... | 2d                              |

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

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

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? .....

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

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

8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? .....

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

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

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

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

(i) Revenue included on Form 990, Part VIII, line 1 .....

(ii) Assets included in Form 990, Part X .....

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

a Revenue included on Form 990, Part VIII, line 1 .....

b Assets included in Form 990, Part X .....

For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule D (Form 990) (Rev. 12-2024)

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

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

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

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

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

|  | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
|--|------------------|----------------|--------------------|----------------------|---------------------|
| 1a Beginning of year balance                     | 1,616,994.       |                |                    |                      |                     |
| b Contributions                                  |                  |                |                    |                      |                     |
| c Net investment earnings, gains, and losses     | 83,782.          |                |                    |                      |                     |
| d Grants or scholarships                         |                  |                |                    |                      |                     |
| e Other expenditures for facilities and programs | 60,000.          |                |                    |                      |                     |
| f Administrative expenses                        |                  |                |                    |                      |                     |
| g End of year balance                            | 1,640,776.       |                |                    |                      |                     |

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment \_\_\_\_\_ %
  - b Permanent endowment 91.3000 %
  - c Term endowment 8.7000 %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |                              | Yes                      | No                                  |
|------------------------------|--------------------------|-------------------------------------|
| (i) Unrelated organizations? | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| (ii) Related organizations?  | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
- b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment** Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

| Description of property   | (a) Cost or other basis (investment) | (b) Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|---|--------------------------------------|---------------------------------|------------------------------|----------------|
| 1a Land   |                                      |                                 |                              |                |
| b Buildings   |                                      |                                 |                              |                |
| c Leasehold improvements  |                                      |                                 |                              |                |
| d Equipment   |                                      | 77,763.                         | 45,637.                      | 32,126.        |
| e Other   |                                      |                                 |                              |                |
| <b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B)) |                                      |                                 |                              | 32,126.        |

**Part VII Investments - Other Securities**

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

| (a) Description of security or category (including name of security)    | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1) Financial derivatives .....   |                |   |
| (2) Closely held equity interests .....                                 |                |   |
| (3) Other .....   |                |   |
| (A)   |                |   |
| (B)   |                |   |
| (C)   |                |   |
| (D)   |                |   |
| (E)   |                |   |
| (F)   |                |   |
| (G)   |                |   |
| (H)   |                |   |
| <b>Total.</b> (Col. (b) must equal Form 990, Part X, line 12, col. (B)) |                |   |

**Part VIII Investments - Program Related.**

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

| (a) Description of investment   | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1)   |                |   |
| (2)   |                |   |
| (3)   |                |   |
| (4)   |                |   |
| (5)   |                |   |
| (6)   |                |   |
| (7)   |                |   |
| (8)   |                |   |
| (9)   |                |   |
| <b>Total.</b> (Col. (b) must equal Form 990, Part X, line 13, col. (B)) |                |   |

**Part IX Other Assets**

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

| (a) Description   | (b) Book value |
|---|----------------|
| (1)   |                |
| (2)   |                |
| (3)   |                |
| (4)   |                |
| (5)   |                |
| (6)   |                |
| (7)   |                |
| (8)   |                |
| (9)   |                |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, line 15, col. (B)) |                |

**Part X Other Liabilities**

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

| 1. (a) Description of liability   | (b) Book value |
|---|----------------|
| (1) Federal income taxes  |                |
| (2) LEASE LIABILITY - SHORT TERM  | 9,633.         |
| (3)   |                |
| (4)   |                |
| (5)   |                |
| (6)   |                |
| (7)   |                |
| (8)   |                |
| (9)   |                |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, line 25, col. (B)) | 9,633.         |

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

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

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

|          |  |           |            |
|----------|--|-----------|------------|
| <b>1</b> | Total revenue, gains, and other support per audited financial statements                       | <b>1</b>  | 3,577,785. |
| <b>2</b> | Amounts included on line 1 but not on Form 990, Part VIII, line 12:                            |           |            |
| <b>a</b> | Net unrealized gains (losses) on investments   | <b>2a</b> | 126,816.   |
| <b>b</b> | Donated services and use of facilities   | <b>2b</b> | 554,815.   |
| <b>c</b> | Recoveries of prior year grants  | <b>2c</b> |            |
| <b>d</b> | Other (Describe in Part XIII.)   | <b>2d</b> |            |
| <b>e</b> | Add lines 2a through 2d  | <b>2e</b> | 681,631.   |
| <b>3</b> | Subtract line 2e from line 1   | <b>3</b>  | 2,896,154. |
| <b>4</b> | Amounts included on Form 990, Part VIII, line 12, but not on line 1:                           |           |            |
| <b>a</b> | Investment expenses not included on Form 990, Part VIII, line 7b                               | <b>4a</b> | 12,927.    |
| <b>b</b> | Other (Describe in Part XIII.)   | <b>4b</b> | -38,424.   |
| <b>c</b> | Add lines 4a and 4b  | <b>4c</b> | -25,497.   |
| <b>5</b> | Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) | <b>5</b>  | 2,870,657. |

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

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

|          |   |           |            |
|----------|---|-----------|------------|
| <b>1</b> | Total expenses and losses per audited financial statements                                      | <b>1</b>  | 2,446,262. |
| <b>2</b> | Amounts included on line 1 but not on Form 990, Part IX, line 25:                               |           |            |
| <b>a</b> | Donated services and use of facilities  | <b>2a</b> | 554,815.   |
| <b>b</b> | Prior year adjustments  | <b>2b</b> |            |
| <b>c</b> | Other losses  | <b>2c</b> |            |
| <b>d</b> | Other (Describe in Part XIII.)  | <b>2d</b> | 38,424.    |
| <b>e</b> | Add lines 2a through 2d   | <b>2e</b> | 593,239.   |
| <b>3</b> | Subtract line 2e from line 1  | <b>3</b>  | 1,853,023. |
| <b>4</b> | Amounts included on Form 990, Part IX, line 25, but not on line 1:                              |           |            |
| <b>a</b> | Investment expenses not included on Form 990, Part VIII, line 7b                                | <b>4a</b> | 12,927.    |
| <b>b</b> | Other (Describe in Part XIII.)  | <b>4b</b> |            |
| <b>c</b> | Add lines 4a and 4b   | <b>4c</b> | 12,927.    |
| <b>5</b> | Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) | <b>5</b>  | 1,865,950. |

**Part XIII Supplemental Information**

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

**PART X, LINE 2:**

THE PREPARATION OF FINANCIAL STATEMENTS IN CONFORMITY WITH ACCOUNTING PRINCIPLES GENERALLY ACCEPTED IN THE UNITED STATES OF AMERICA REQUIRES THE FOUNDATION TO REPORT INFORMATION REGARDING ITS EXPOSURE TO VARIOUS TAX POSITIONS TAKEN BY THE FOUNDATION. THE FOUNDATION HAS DETERMINED WHETHER ANY TAX POSITIONS HAVE MET THE RECOGNITION THRESHOLD AND HAVE MEASURED THE FOUNDATION'S EXPOSURE TO THOSE TAX POSITIONS. MANAGEMENT BELIEVES THAT THE FOUNDATION HAS ADEQUATELY ADDRESSED ALL RELEVANT TAX POSITIONS AND THAT THERE ARE NO UNRECORDED TAX LIABILITIES. FEDERAL AND STATE TAX AUTHORITIES GENERALLY HAVE THE RIGHT TO EXAMINE AND AUDIT THE PREVIOUS THREE YEARS OF TAX RETURNS FILED. ANY INTEREST OR PENALTIES ASSESSED TO THE FOUNDATION, OF WHICH THERE WERE NONE, ARE RECORDED IN ADMINISTRATIVE EXPENSES.

**PART XI, LINE 4B - OTHER ADJUSTMENTS:**

SPECIAL EVENTS EXPENSE -38,424.

**PART XII, LINE 2D - OTHER ADJUSTMENTS:**

SPECIAL EVENTS EXPENSE 38,424.



**SCHEDULE F  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Statement of Activities Outside the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

Attach to Form 990.

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

OMB No. 1545-0047

**Open to Public  
Inspection**

Name of the organization: **CREUTZFELDT-JAKOB DISEASE FOUNDATION INC**  
Employer identification number: **65-0404623**

**Part I General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

**1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? .....  **Yes**  **No**

**2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

**3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

| (a) Region  | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in the region | (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region | (f) Total expenditures for and investments in the region |
|---|-------------------------------------|--|--|--|--|
| EUROPE (INCLUDING ICELAND & GREENLAND)                  |                                     |  | GRANTS TO RECIPIENTS   |  | 299,804.   |
| NORTH AMERICA   |                                     |  | GRANTS TO RECIPIENTS   |  | 203,116.   |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
| <b>3 a</b> Subtotal .....                               | 0                                   | 0  |  |  | 502,920.   |
| <b>b</b> Total from continuation sheets to Part I ..... | 0                                   | 0  |  |  | 0.   |
| <b>c Totals</b> (add lines 3a and 3b) .....             | 0                                   | 0  |  |  | 502,920.   |



**Part II** Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region   | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|----------------------------|--|--|----------------------|--------------------------|---------------------------------|----------------------------------|---------------------------------------|---|
|                            |  | EUROPE (INCLUDING ICELAND & GREENLAND)                       | CJD RESEARCH         | 99,944                   | WIRE TRANSFER                   | 0.                               |                                       |   |
|                            |  | EUROPE (INCLUDING ICELAND & GREENLAND)                       | CJD RESEARCH         | 99,860                   | WIRE TRANSFER                   | 0.                               |                                       |   |
|                            |  | NORTH AMERICA - CANADA AND MEXICO, BUT NOT THE UNITED STATES | CJD RESEARCH         | 3,116                    | WIRE TRANSFER                   | 0.                               |                                       |   |
|                            |  | NORTH AMERICA - CANADA AND MEXICO, BUT NOT THE UNITED STATES | CJD RESEARCH         | 200,000                  | WIRE TRANSFER                   | 0.                               |                                       |   |
|                            |  | EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,   | CJD RESEARCH         | 100,000                  | WIRE TRANSFER                   | 0.                               |                                       |   |
|                            |  |  |                      |                          |                                 |                                  |                                       |   |
|                            |  |  |                      |                          |                                 |                                  |                                       |   |
|                            |  |  |                      |                          |                                 |                                  |                                       |   |

**2** Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter .....

**3** Enter total number of other organizations or entities .....



**Part IV Foreign Forms**

- 1** Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)* .....  Yes  No
- 2** Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 3520 and 3520-A; don't file with Form 990)* .....  Yes  No
- 3** Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see the Instructions for Form 5471)* .....  Yes  No
- 4** Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)* .....  Yes  No
- 5** Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)* .....  Yes  No
- 6** Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)* .....  Yes  No

**Part V Supplemental Information**

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

SCHEDULE F, PAGE 1, PART I, LINE 2

THE ORGANIZATION AWARDS GRANTS BASED ON PROPOSED RESEARCH BUDGETS AND MONITORS THE STATUS OF THE RESEARCH THROUGH VARIOUS MEANS AS WELL AS UPDATES AND WRITTEN REPORTS ON PROJECTS PROVIDED AT THE FAMILY CONFERENCE.

SCHEDULE F, PAGE 1, PART I, LINE 3

SWITZERLAND: \$99,944

SPAIN: \$99,860

CANADA: \$203,116

GERMANY: \$100,000



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

|                 |  | (a) Event #1  | (b) Event #2 | (c) Other events | (d) Total events                |
|-----------------|--|---|--------------|------------------|---------------------------------|
|                 |  | STRIDES FOR CJD   |              | NONE             | (add col. (a) through col. (c)) |
|                 |  | (event type)  | (event type) | (total number)   |                                 |
| Revenue         | 1  | Gross receipts  | 757,855.     |                  | 757,855.                        |
|                 | 2  | Less: Contributions   | 743,496.     |                  | 743,496.                        |
|                 | 3  | Gross income (line 1 minus line 2)                          | 14,359.      |                  | 14,359.                         |
| Direct Expenses | 4  | Cash prizes   |              |                  |                                 |
|                 | 5  | Noncash prizes  |              |                  |                                 |
|                 | 6  | Rent/facility costs   | 5,335.       |                  | 5,335.                          |
|                 | 7  | Food and beverages  |              |                  |                                 |
|                 | 8  | Entertainment   |              |                  |                                 |
|                 | 9  | Other direct expenses                                       | 47,448.      |                  | 47,448.                         |
|                 | 10   | Direct expense summary. Add lines 4 through 9 in column (d) |              |                  | 52,783.                         |
| 11              | Net income summary. Subtract line 10 from line 3, column (d) |   |              | -38,424.         |                                 |

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

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

9 Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_  
 a Is the organization licensed to conduct gaming activities in each of these states?  Yes  No  
 b If "No," explain: \_\_\_\_\_

10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?  Yes  No  
 b If "Yes," explain: \_\_\_\_\_







**SCHEDULE I  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

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

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

OMB No. 1545-0047

Open to Public  
Inspection

Name of the organization

CREUTZFELDT-JAKOB DISEASE FOUNDATION INC

Employer identification number  
65-0404623

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

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

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

| 1 (a) Name and address of organization or government  | (b) EIN    | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
|---|------------|---------------------------------|--------------------------|----------------------------------|---|---------------------------------------|------------------------------------|
| CASE WESTERN RESERVE<br>109000 EUCLID AVENUE<br>CLEVELAND, OH 44106   | 34-1018922 | 501(C)(3)                       | 100,000.                 | 0.                               |   |                                       | RESEARCH                           |
| NATIONAL INSTITUTE OF ALLERGY AND<br>INFECTIOUS DISEASES - 5601 FISHERS<br>LAND SUITE 2G, MSC 9804 -<br>BETHESDA, MD 20892-9804 | 53-0196960 |                                 | 100,000.                 | 0.                               |   |                                       | RESEARCH                           |
|   |            |                                 |                          |                                  |   |                                       |                                    |
|   |            |                                 |                          |                                  |   |                                       |                                    |
|   |            |                                 |                          |                                  |   |                                       |                                    |
|   |            |                                 |                          |                                  |   |                                       |                                    |

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



**SCHEDULE O  
(Form 990)**

(Rev. December 2024)

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 Form 990-EZ.

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

OMB No. 1545-0047

Open to Public  
Inspection

|   |   |
|---|---|
| Name of the organization<br><b>CREUTZFELDT-JAKOB DISEASE FOUNDATION INC</b> | Employer identification number<br><b>65-0404623</b> |
|---|---|

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:  
SUPPORT MEDICAL EDUCATION AND RESEARCH.

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:  
 THE MISSION OF THE CREUTZFELDT-JAKOB DISEASE FOUNDATION IS TO SUPPORT FAMILIES AFFECTED BY PRION DISEASE, RAISE AWARENESS, SUPPORT MEDICAL EDUCATION, AND FUND RESEARCH. WE CARRY OUT THIS MISSION THROUGH:

- FAMILY SUPPORT INCLUDING A 7-DAY HELPLINE, REFERRALS, SUPPORT GROUPS AND TELECONFERENCE SPEAKER SERIES
- EDUCATION AND INFORMATION FOR FAMILIES, CAREGIVERS, MEDICAL PROFESSIONALS, FUNERAL PROFESSIONALS, AND INFECTION CONTROL SPECIALISTS
- ADVOCACY WITH PUBLIC POLICY MAKERS
- ANNUAL FAMILY CONFERENCE THAT BRINGS TOGETHER AFFECTED FAMILIES AND PRION DISEASE EXPERTS
- SUPPORT GROUPS FOR FAMILIES AFFECTED BY CJD
- COLLABORATION WITH SCIENTISTS, CLINICIANS, MEDICAL CENTERS, HEALTH AUTHORITIES, PROFESSIONAL ORGANIZATIONS, AND INTERNATIONAL PATIENT ASSOCIATIONS
- COMMUNICATION OF CURRENT RESEARCH AND FOUNDATION ACTIVITIES VIA ANNUAL CONFERENCE, WEBSITE, SOCIAL MEDIA, EMAILS, AND FAMILY TELECONFERENCES
- RESEARCH GRANT PROGRAM, WHICH INCLUDES NATIONAL AND INTERNATIONAL AWARDEES SELECTED BY OUR SCIENTIFIC ADVISORY COMMITTEE

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:  
 MEDICAL PROFESSIONALS, FUNERAL DIRECTORS, AND INFECTION CONTROL SPECIALISTS. WE SENT CAREGIVING BINDERS TO MORE THAN 174 FAMILIES AND HOSPICE PROVIDERS.

AT OUR 2024 CJD FOUNDATION FAMILY CONFERENCE, A TOTAL OF 155 FAMILY MEMBERS, PRION DISEASE EXPERTS, AND PROFESSIONALS ATTENDED. CONFERENCE SESSIONS INCLUDED AN UPDATE FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION, RESEARCH UPDATES, AND INFORMATION ON SURVEILLANCE, TREATMENT, AND EARLY DIAGNOSIS OF CJD.

SUPPORT GROUPS, WEBINARS AND SPEAKER SERIES: WE HOSTED 43 TELECONFERENCE SUPPORT GROUPS IN 2024. THESE CALLS ALLOW CONSTITUENTS WHO CANNOT ATTEND IN-PERSON EVENTS TO ACCESS AN EXPERT AND ADDRESS THEIR QUESTIONS AND CONCERNS. INTERVIEWS WITH PRION DISEASE EXPERTS WERE RECORDED AND POSTED TO THE CJD FOUNDATION WEBSITE.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:  
 - BAYSTATE UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL  
 - CAPE COD FALMOUTH HOSPITAL IN FALMOUTH, MA.

FUNERAL EDUCATION PRESENTATIONS WERE HELD IN:  
 - INDIANAPOLIS, INDIANA

WE ALSO RESPONDED TO REQUESTS FOR INFORMATION FROM 70 MEDICAL PROFESSIONALS VIA OUR HELPLINE, AND MADE INFORMATION AVAILABLE TO

|  |  |
|--|--|
| Name of the organization<br>CREUTZFELDT-JAKOB DISEASE FOUNDATION INC | Employer identification number<br>65-0404623 |
|--|--|

MEDICAL, INFECTIOUS DISEASE, HOSPICE AND GENETIC COUNSELING PROFESSIONALS THROUGH OUR WEBSITE, EDUCATIONAL BINDERS, AND ANNUAL CONFERENCE WHICH IS RECORDED AND POSTED ON OUR WEBSITE.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:  
ADVOCACY WITH POLITICAL REPRESENTATIVES AND PUBLIC POLICY MAKERS  
EXPENSES \$ 46,831. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 2:  
JACOB SCHWISTER (BOARD MEMBER) AND TIM SCHWISTER (BOARD MEMBERS) ARE FAMILY.

FORM 990, PART VI, SECTION B, LINE 11B:  
THE CREUTZFELDT-JAKOB DISEASE FOUNDATION RECEIVES A COPY OF FORM 990 TO REVIEW BEFORE THE RETURN IS FILED. FORM 990 IS REVIEWED BY THE PRESIDENT AND BOARD OF DIRECTORS FOR REVIEW OF ACCURACY AND COMPLETENESS.

FORM 990, PART VI, SECTION B, LINE 12C:  
THE CONFLICT OF INTEREST POLICY IS ENFORCED BY THE BOARD AND BOARD MEMBERS WHO ARE REQUIRED TO DISCLOSE KNOWN CONFLICTS.

FORM 990, PART VI, SECTION B, LINE 15A:  
THE ORGANIZATION RESEARCHED AND COMPARED THE SALARY OF OTHER CEOS WORKING FOR OTHER NON-PROFIT ORGANIZATIONS OF ABOUT THE SAME SIZE. ONCE A FAIR AND COMPARABLE COMPENSATION WAS DETERMINED THE ORGANIZATION PRESENTED THE SALARY TO THE EXECUTIVE BOARD AND THE FULL BOARD FOR APPROVAL. THE CEO WAS NOT PRESENT DURING THE VOTE ON COMPENSATION.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:  
CA, CO, CT, DE, FL, IL, KS, MA, MD, NJ, NY, OH, OR, PA, VA, WA, WI, WV

FORM 990, PART VI, SECTION C, LINE 19:  
THE ORGANIZATION MAKES ITS GOVERNING DOCUMENTS AND FINANCIAL STATEMENTS AVAILABLE UPON REQUEST.

FORM 990, PAGE 1, PART I, LINE 6  
THE CJD FOUNDATION'S VOLUNTEERS INCLUDE THOSE WHO HAVE HAD A LOVED ONE AFFECTED, OR WHO UNDERSTAND THE IMPACT OF PRION DISEASE. THEY ARE PASSIONATE ABOUT OUR MISSION AND WANT TO RAISE AWARENESS, EDUCATE MEDICAL PROFESSIONALS AND THE PUBLIC, AND SUPPORT RESEARCH FOR A CURE. VOLUNTEER ROLES INCLUDE ASSISTING WITH OUR HELPLINE, ADVOCACY, MEDICAL EDUCATION, AND FAMILY SUPPORT PROGRAMS AND PEER COUSELING THROUGH SUPPORT GROUPS. SOME VOLUNTEER THEIR SKILLS IN MARKETING, WEB DESIGN, PUBLIC RELATIONS, LEGAL AND FINANCIAL AREAS. OTHERS REVIEW RESEARCH GRANT APPLICATIONS OR ASSIST WITH OUR FAMILY CONFERENCE, FAMILY WORKSHIPS, OR FUNDRAISING/AWARENESS-RAISING EVENTS. IN TOTAL, APPROXIMATELY 350 CONTRIBUTED OVER 6,500 HOURS. WITHOUT THE EFFORTS OF THESE VOLUNTEERS, WE COULD NOT HAVE SERVED OUR COMMUNITY WITH THE PROGRAMS WE OFFER.

FORM 990, PAGE 1, PART I, LINE 2  
THE ORGANIZATION AWARDS GRANTS BASED ON PROPOSED RESEARCH BUDGETS AND MONITORS THE STATUS OF THE RESEARCH THROUGH VARIOUS MEANS AS WELL AS UPDATES AND WRITTEN REPORTS PROVIDED AT FAMILY CONFERENCE.

