

Form 990EZ

Short Form

OMB No. 1545-0047

Return of Organization Exempt From Income Tax

2024

Department of the Treasury Internal Revenue Service

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

Open to Public Inspection

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

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

A For the 2024 calendar year, or tax year beginning 01-01-2024, and ending 12-31-2024

B Check if applicable:

- Address change
Name change
Initial return
Final return/terminated
Amended return
Application pending

C Name of organization SHINE SYNDROME FOUNDATION
Number and street (or P. O. box, if mail is not delivered to street address) Room/suite
255 E Fifth St Ste 1900
City or town, state or province, country, and ZIP or foreign postal code
Cincinnati, OH 45202

D Employer identification number 87-4703593
E Telephone number (385) 321-3694
F Group Exemption Number

G Accounting Method: Cash Accrual Other (specify)

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

I Website: https://www.dlg4shine.org/

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

K Form of organization: Corporation Trust Association Other

L Add lines 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total assets (Part II, column (B) below) are \$500,000 or more, file Form 990 instead of Form 990-EZ \$ 122,251

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

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

Table with 3 columns: Description, Amount, and Total. Rows include Revenue (1-9), Expenses (10-17), and Net Assets (18-21). Total revenue is 121,917 and total expenses is 30,041.

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

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

	(A) Beginning of year	(B) End of year
22 Cash, savings, and investments	34,235	126,111
23 Land and buildings		
24 Other assets (describe in Schedule O)		
25 Total assets	34,235	126,111
26 Total liabilities (describe in Schedule O).		
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	34,235	126,111

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

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

What is the organization's primary exempt purpose?
 Our mission is to improve the lives of individuals with DLG4-related Synaptopathy by supporting research, developing treatments and therapies, and providing a community of support. We understand the challenges that families face when dealing with this rare disease, and we are committed to making a difference. By collaborating with researchers, healthcare professionals, and other organizations, we aim to accelerate medical advances focused on the treatment of DLG4 Synaptopathy.

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

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

28a Sent members who are effected by DLG4 SHINE, Medical Considerations Documents (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		3,123
29a FDA Patient Listening Session (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		
30a Scientific Webinars (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		
Ongoing Research Projects Progress (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		
Ongoing Community Support including Website and Social Media Development (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		6,742
Research Asset Development (iPSC, Mouse, and Rat Development) (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		875
Scientific Conference Representation (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		2,319
31a Other program services (describe in Schedule O) (Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>		
32 Total program service expenses (add lines 28a through 31a) <input type="checkbox"/>		13,059

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

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

(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
Tim Stuart President	10.00	0	0	0
Marie-France Gervais President	30.00	0	0	0
Justin Neduchal Vice President/Ethics Officer	5.00	0	0	0
Payal Patel Vice President of Development	30.00	0	0	0
Melanie Queen Treasurer	20.00	0	0	0
Courtney Roche Secretary	15.00	0	0	0
Sabrina Merchant MD Director of Science and Clinical Development	30.00	0	0	0
Dana Opar Director of Marketing	20.00	0	0	0