

# Return of Organization Exempt From Income Tax

**2018**

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

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

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

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

**A** For the 2018 calendar year, or tax year beginning January 1, 2018, and ending December 31, 2018

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

**C** Name of organization: Glut1 Deficiency Foundation, Inc.  
 Doing business as: Glut1 Deficiency Foundation  
 Number and street (or P.O. box if mail is not delivered to street address): PO Box 737  
 Room/suite: \_\_\_\_\_  
 City or town, state or province, country, and ZIP or foreign postal code: Owingsville, KY 40360

**D** Employer identification number: 45-2190535

**E** Telephone number: 859-585-2538

**G** Gross receipts \$: 226,360.70

**F** Name and address of principal officer:  
Glenna Steele, Executive Director PO Box 737 Owingsville, KY 40360

**H(a)** Is this a group return for subsidiaries?  Yes  No  
**H(b)** Are all subsidiaries included?  Yes  No  
 If "No," attach a list. (see instructions)

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

**J** Website: www.G1DFoundation.org

**H(c)** Group exemption number ▶ \_\_\_\_\_

**K** Form of organization:  Corporation  Trust  Association  Other ▶ \_\_\_\_\_

**L** Year of formation: 2011 **M** State of legal domicile: IN

**Part I Summary**

**1** Briefly describe the organization's mission or most significant activities: The Glut1 Deficiency Foundation is a nonprofit family organization dedicated to improving the lives of those in the Glut1 Deficiency community through its mission of increased awarene improved education, advocacy for patients and families, and support and funding for research.

**2** Check this box  if the organization discontinued its operations or disposed of more than 25% of its net assets.

**3** Number of voting members of the governing body (Part VI, line 1a) 3

**4** Number of independent voting members of the governing body (Part VI, line 1b) 8

**5** Total number of individuals employed in calendar year 2018 (Part V, line 2a) 1

**6** Total number of volunteers (estimate if necessary) 15

**7a** Total unrelated business revenue from Part VIII, column (C), line 12 0

**7b** Net unrelated business taxable income from Form 990-T, line 38 0

		Prior Year	Current Year
<b>Revenue</b>	<b>8</b> Contributions and grants (Part VIII, line 1h)	141,440	187,578
	<b>9</b> Program service revenue (Part VIII, line 2g)	31,244	37,625
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	0	0
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	0	1158
	<b>12</b> Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	172,684	226,361
<b>Expenses</b>	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1–3)	80,000	0
	<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)	0	0
	<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	21,657	40,416
	<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)	0	0
	<b>b</b> Total fundraising expenses (Part IX, column (D), line 25) ▶ <u>2,529</u>		
	<b>17</b> Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	98,003	59,945
<b>18</b> Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	199,660	102,890	
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	(26,976)	123,471	
<b>Net Assets or Fund Balances</b>	<b>20</b> Total assets (Part X, line 16)	Beginning of Current Year 73,361	End of Year 194,209
	<b>21</b> Total liabilities (Part X, line 26)	(5160)	(88)
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	68,201	194,121

**Part II Signature Block**

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

**Sign Here** ▶ Glenna S. Steele Signature of officer Date 3-20-19  
 ▶ Glenna S. Steele Type or print name and title Date 3-20-19

**Paid Preparer Use Only**

Print/Type preparer's name: \_\_\_\_\_ Preparer's signature: \_\_\_\_\_ Date: \_\_\_\_\_ Check  if self-employed PTIN: \_\_\_\_\_

Firm's name ▶ \_\_\_\_\_ Firm's EIN ▶ \_\_\_\_\_  
 Firm's address ▶ \_\_\_\_\_ Phone no. \_\_\_\_\_

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

**Part III Statement of Program Service Accomplishments**

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

**1** Briefly describe the organization's mission:  
The Glut1 Deficiency Foundation is a nonprofit family organization dedicated to improving the lives of those in the Glut1 Deficiency community through its mission of increased awareness, improved education, advocacy for patients and families, and support and funding for research.

**2** Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?  Yes  No  
If "Yes," describe these new services on Schedule O.

**3** Did the organization cease conducting, or make significant changes in how it conducts, any program services?  Yes  No  
If "Yes," describe these changes on Schedule O.

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

**4a** (Code: ) (Expenses \$ 78,089 including grants of \$ ) (Revenue \$ 37,625)

**Education and Awareness Programs:**

The Glut1 Deficiency Foundation has several outreach programs to help raise awareness and spread education. We host bi-ennial conferences where families and professionals come together to meet, share, and learn. We host educational exhibit booths at major national and international professional meetings to help raise awareness and educate healthcare professionals who are in a position to diagnose and treat patients. The G1DF also has online and print resources available to families and healthcare professionals and mails packets of information to various medical professionals and to newly diagnosed families.

7 Educational Exhibits - American Academy of Neurology, American Epilepsy Society, American College of Medical Genetics, Epilepsy Awareness Day Disneyland, European Conference on Glut1 Deficiency, European Academy of Neurology, Society for Neuroscience, National Ataxia Foundation professional conferences and meetings

The next G1DF biennial conference will be in 2019, with some planning expenses incurred and paid in 2018.

**4b** (Code: ) (Expenses \$ 1,556 including grants of \$ 0) (Revenue \$ 0)

**Advocacy Programs:**

The Glut1 Deficiency Foundation is engaged in collaborating with national and international rare disease patient advocacy groups to provide a representative voice for Glut1 Deficiency patients and families in public discussion and policy issues. The G1DF advocates for families and patients across school, healthcare, and disability programs to make sure the challenges of the condition are understood and that patient rights are being protected. Advocacy efforts for 2018 included National Organization of Rare Disorders membership and various webinar trainings, NORD Patient Advocacy Summit attendance, ICD10-CM diagnosis code proposal, National Health Council meeting, Nutrition Equity Act meetings, and rare disease advocacy training and meetings.

**4c** (Code: ) (Expenses \$ 0 including grants of \$ 0) (Revenue \$ 0)

**Support and Funding for Research Programs:**

The Glut1 Deficiency Foundation has a research grant award program where funds are awarded for scientific research related to the understanding, treatment, and cure of Glut1 Deficiency. Funds are set aside from donations and are distributed in grant award cycles when amounts reach levels that make grant awards possible. No grant awards were given in 2018; however, funds have been held over for a grant award cycle in the spring of 2019.

**4d** Other program services (Describe in Schedule O.)  
(Expenses \$ including grants of \$ ) (Revenue \$ )

**4e** Total program service expenses 79,645

**Part IV Checklist of Required Schedules**

	Yes	No
<b>1</b> Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
<b>2</b> Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
<b>3</b> Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>4</b> <b>Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>5</b> Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>6</b> Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>7</b> Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>8</b> Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>9</b> Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>10</b> Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>11</b> If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
<b>a</b> Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>b</b> Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>c</b> Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>d</b> Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>e</b> Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>f</b> Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>12a</b> Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>b</b> Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(iii)? <i>If "Yes," complete Schedule E</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>b</b> Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>15</b> Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>16</b> Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>17</b> Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I (see instructions)</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>18</b> Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>19</b> Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>20a</b> Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>21</b> Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>



Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question number, Question text, and Yes/No columns. Rows include questions 22 through 38 regarding grants, compensation, tax-exempt bonds, and organizational transactions.

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with 3 columns: Question number, Question text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and backup withholding rules.

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

		Yes	No
<b>2a</b>	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return <b>2a</b> <span style="float:right">1</span>		
<b>b</b>	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	<input checked="" type="checkbox"/>	
<b>3a</b>	Did the organization have unrelated business gross income of \$1,000 or more during the year?		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O		
<b>4a</b>	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," enter the name of the foreign country: <span style="border-bottom: 1px solid black; display: inline-block; width: 150px;"></span> See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
<b>5a</b>	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		<input checked="" type="checkbox"/>
<b>b</b>	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		<input checked="" type="checkbox"/>
<b>c</b>	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
<b>6a</b>	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
<b>7</b>	<b>Organizations that may receive deductible contributions under section 170(c).</b>		
<b>a</b>	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
<b>c</b>	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		<input checked="" type="checkbox"/>
<b>d</b>	If "Yes," indicate the number of Forms 8282 filed during the year <b>7d</b>		
<b>e</b>	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		<input checked="" type="checkbox"/>
<b>f</b>	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		<input checked="" type="checkbox"/>
<b>g</b>	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
<b>h</b>	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
<b>8</b>	<b>Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		<input checked="" type="checkbox"/>
<b>9</b>	<b>Sponsoring organizations maintaining donor advised funds.</b>		
<b>a</b>	Did the sponsoring organization make any taxable distributions under section 4966?		<input checked="" type="checkbox"/>
<b>b</b>	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		<input checked="" type="checkbox"/>
<b>10</b>	<b>Section 501(c)(7) organizations.</b> Enter:		
<b>a</b>	Initiation fees and capital contributions included on Part VIII, line 12 <b>10a</b>		
<b>b</b>	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities <b>10b</b>		
<b>11</b>	<b>Section 501(c)(12) organizations.</b> Enter:		
<b>a</b>	Gross income from members or shareholders <b>11a</b>		
<b>b</b>	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.) <b>11b</b>		
<b>12a</b>	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?		
<b>b</b>	If "Yes," enter the amount of tax-exempt interest received or accrued during the year <b>12b</b>		
<b>13</b>	<b>Section 501(c)(29) qualified nonprofit health insurance issuers.</b>		
<b>a</b>	Is the organization licensed to issue qualified health plans in more than one state? <b>Note.</b> See the instructions for additional information the organization must report on Schedule O.		
<b>b</b>	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans <b>13b</b>		
<b>c</b>	Enter the amount of reserves on hand <b>13c</b>		
<b>14a</b>	Did the organization receive any payments for indoor tanning services during the tax year?		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O <b>14b</b>		
<b>15</b>	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N.		<input checked="" type="checkbox"/>
<b>16</b>	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.		<input checked="" type="checkbox"/>