

Return of Organization Exempt From Income Tax

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

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

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

Open to Public Inspection

A For the 2019 calendar year, or tax year beginning January 1, 2019, and ending December 31, 2019

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization <u>Glut1 Deficiency Foundation, Inc.</u>		D Employer identification number 45-2190535
	Doing business as		E Telephone number 859-585-2538
Number and street (or P.O. box if mail is not delivered to street address) Room/suite <u>PO Box 737</u>			
City or town, state or province, country, and ZIP or foreign postal code <u>Owingsville, KY 40360</u>		G Gross receipts \$ <u>335,465</u>	
F Name and address of principal officer: <u>Glenna Steele, Executive Director PO Box 737 Owingsville, KY 40360</u>		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions)	
J Website: <u>www.G1DFoundation.org</u>		H(c) Group exemption number ▶	
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		L Year of formation: <u>2011</u>	M State of legal domicile: <u>IN</u>

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: <u>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.</u>		
	2 Check this box <input type="checkbox"/> 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	8
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	8
	5 Total number of individuals employed in calendar year 2019 (Part V, line 2a)	5	1
	6 Total number of volunteers (estimate if necessary)	6	15
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
b Net unrelated business taxable income from Form 990-T, line 39	7b	0	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9 Program service revenue (Part VIII, line 2g)	187,578	204,776
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	37,625	129,993
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	0	0
	12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,158	696
	13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)	226,361	335,465
Expenses	14 Benefits paid to or for members (Part IX, column (A), line 4)	0	181,505
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	0	0
	16a Professional fundraising fees (Part IX, column (A), line 11e)	40,416	44,352
	b Total fundraising expenses (Part IX, column (D), line 25) ▶	0	0
	17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	59,945	190,397
	18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	102,890	416,254
19 Revenue less expenses. Subtract line 18 from line 12	123,471	(80,789)	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year	End of Year
	21 Total liabilities (Part X, line 26)	194,209	98,002
	22 Net assets or fund balances. Subtract line 21 from line 20	(88)	(703)
		194,121	97,299

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	<u>Glenna S. Steele</u> Signature of officer	<u>3-19-2020</u> Date
	<u>Glenna S. Steele Executive Director</u> Type or print name and title	

Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN
	Firm's name ▶	Firm's EIN ▶			
	Firm's address ▶	Phone 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?
3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?
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 \$ 191,298 including grants of \$ 19,505) (Revenue \$ 129,993)

Education and Awareness Programs:

The Glut1 Deficiency Foundation has several outreach programs to help raise awareness and spread education. We host biennial 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. We distributed 2,500 print brochures in 2019, welcomed 400 weekly unique visitors to our website, and provide information to 3,500 social media followers. Our 8th Biennial Conference was held in July of 2019 in Washington, DC hosted 430 attendees and provided travel stipends for adult patients through a conference grant from PCORI. We hosted six educational exhibits at major professional medical meetings across the United States. We provided 125 welcome packets with information and resources to newly diagnosed patients and families. We conducted a first-ever survey of adult patients and organized presentations, summary reports, and a research publication (in process). We also have awareness merchandise available for sale on our website.

4b (Code:) (Expenses \$ 7,943 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 are understood and that patient rights are being protected. Advocacy efforts for 2019 included National Organization for Rare 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 2019 included National Organization for Rare Disorders (NORD) membership and various webinar trainings, NORD Patient Advocacy Summit attendance, ICD-10 code proposal presentation, and Global Genes membership and multiple trainings. We also had special presentations at our family conference for issues around disability, social security, schooling, and financial planning.

4c (Code:) (Expenses \$ 163,500 including grants of \$ 162,000) (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 and impactful. In 2019, the Glut1 Deficiency Foundation funded five grants at three institutions, totaling \$187,000. Grants funds are delivered in two installments, one at the beginning and one at the reporting midpoint of each project. All but \$25,000 was delivered in 2019, with the remaining \$25,000 payable in March of 2020. An additional \$1,250 was paid for statistical analysis for the adult experiences in Glut1 Deficiency project, which provided insights and data that were shared at our conference and are in the publication process.

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

4e Total program service expenses 396,779

Part IV Checklist of Required Schedules

	Yes	No
1 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"/>
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3 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"/>
4 Section 501(c)(3) organizations. 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"/>
5 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"/>
6 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"/>
7 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"/>
8 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"/>
9 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"/>
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
11 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.		
a 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 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"/>
c 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"/>
d 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"/>
e 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"/>
f 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"/>
12a 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 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"/>
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
14a Did the organization maintain an office, employees, or agents outside of the United States?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
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"/>
15 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"/>
16 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"/>
17 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"/>
18 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"/>
19 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"/>
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
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"/>
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Part IV Checklist of Required Schedules *(continued)*

		Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	✓	
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>		✓
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		✓
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		✓
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		✓
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		✓
25a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		✓
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>		✓
26	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i>		✓
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	✓	
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions, for applicable filing thresholds, conditions, and exceptions):		
a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>		✓
b	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		✓
c	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>		✓
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>		✓
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		✓
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		✓
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		✓
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		✓
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		✓
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		✓
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		✓
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		✓
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>		✓
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O.	✓	

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

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	✓	

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

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