

Form **990**
(Rev. January 2020)
Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

OMB No 1545-0047

2019

Open to Public Inspection

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

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

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

A For the 2019 calendar year, or tax year beginning January 1, 2019, and ending December 31, 2019	
B Check if applicable: ☐ Address change ☐ Name change ☐ Initial return ☐ Final return/terminated ☐ Amended return ☐ Application pending	C Name of organization <u>Glut1 Deficiency Foundation, Inc.</u> Doing business as _____ 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> D Employer identification number <u>45-2190535</u> E Telephone number <u>859-585-2538</u> G Gross receipts \$ <u>335,465</u> H(a) Is this a group return for subordinates? ☐ Yes ☒ No H(b) Are all subordinates included? ☐ Yes ☐ No If "No," attach a list (see instructions) H(c) Group exemption number ▶ _____ I Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () ◀ (insert no) ☐ 4947(a)(1) or ☐ 527 J Website: ▶ <u>www.G1DFoundation.org</u> K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ 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 ☐ 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, 9c, 10c, and 11e)	37,625	129,993
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 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
	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
Expenses	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)

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</u> Type or print name and title	<u>Executive Director</u>			
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

For Paperwork Reduction Act Notice, see the separate instructions.

Cat. No 11282Y

Form 990 (2019)

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Part III Statement of Program Service AccomplishmentsCheck 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 \$ 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

ABI LD

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	1 ✓	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	2 ✓	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3	✓
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? If "Yes," complete Schedule C, Part II	4	✓
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? If "Yes," complete Schedule C, Part III	5	✓
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? If "Yes," complete Schedule D, Part I	6	✓
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7	✓
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	8	✓
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? If "Yes," complete Schedule D, Part IV	9	✓
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? If "Yes," complete Schedule D, Part V	10	✓
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? If "Yes," complete Schedule D, Part VI	11a	✓
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? If "Yes," complete Schedule D, Part VII	11b	✓
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? If "Yes," complete Schedule D, Part VIII	11c	✓
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? If "Yes," complete Schedule D, Part IX	11d	✓
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	✓
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)? If "Yes," complete Schedule D, Part X	11f	✓
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	12a	✓
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b	✓
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	✓
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	✓
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? If "Yes," complete Schedule F, Parts I and IV	14b	✓
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? If "Yes," complete Schedule F, Parts II and IV	15	✓
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? If "Yes," complete Schedule F, Parts III and IV	16	✓
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? If "Yes," complete Schedule G, Part I (see instructions)	17	✓
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	✓
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	19	✓
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	✓
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	✓
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21 ✓	

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? If "Yes," complete Schedule I, Parts I and III	☒	☐
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? If "Yes," complete Schedule J	☐	☒
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? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a	☐	☒
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? If "Yes," complete Schedule L, Part 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? If "Yes," complete Schedule L, Part 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? If "Yes," complete Schedule L, Part II	☐	☒
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? If "Yes," complete Schedule L, Part III	☒	☐
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? If "Yes," complete Schedule L, Part IV	☐	☒
b A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	☐	☒
c A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If "Yes," complete Schedule L, Part IV	☐	☒
29 Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	☐	☒
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	☐	☒
31 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	☐	☒
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	☐	☒
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? If "Yes," complete Schedule R, Part I	☐	☒
34 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1	☐	☒
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)? If "Yes," complete Schedule R, Part V, line 2	☐	☒
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2	☐	☒
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? If "Yes," complete Schedule R, Part VI	☐	☒
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 ComplianceCheck 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	2a	1
b	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)	2b	✓
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a	✓
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a	✓
b	If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	✓
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	✓
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	6a	✓
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	✓
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	✓
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	✓
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d	
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	✓
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	✓
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h	
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8	✓
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?	9a	✓
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b	✓
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b	
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	13a	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b	
c	Enter the amount of reserves on hand	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	✓
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b	
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N.	15	✓
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16	✓

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 ☐**Section A. Governing Body and Management**

		Yes	No
1a Enter the number of voting members of the governing body at the end of the tax year	1a 8		
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.			
b Enter the number of voting members included on line 1a, above, who are independent	1b 8		
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2		✓
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?	3		✓
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		✓
5 Did the organization become aware during the year of a significant diversion of the organization's assets?	5		✓
6 Did the organization have members or stockholders?	6		✓
7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	7a		✓
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b		✓
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:			
a The governing body?	8a	✓	
b Each committee with authority to act on behalf of the governing body?	8b	✓	
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	9		✓

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

	Yes	No
10a Did the organization have local chapters, branches, or affiliates?	10a	✓
b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	10b	
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	✓
b Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
12a Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	✓
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	✓
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	✓
13 Did the organization have a written whistleblower policy?	13	✓
14 Did the organization have a written document retention and destruction policy?	14	✓
15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
a The organization's CEO, Executive Director, or top management official	15a	✓
b Other officers or key employees of the organization	15b	✓
If "Yes" to line 15a or 15b, describe the process in 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?	16a	✓
b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	16b	

Section C. Disclosure

- 17** List the states with which a copy of this Form 990 is required to be filed ► **Indiana - multiple others for state charity registration**
- 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.
☒ Own website ☒ Another's website ☒ 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 ►
Glenna Steele, Executive Director 1749 Peeled Oak Road Owingsville, Kentucky 40360 859-585-2538

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck 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 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 and/or Box 7 of Form 1099-MISC) 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 instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) 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) Glenna Steele Executive Director	50			✓				41,200	0	0
(2) Jason Meyers President	5	✓						0	0	0
(3) April York Vice President	3	✓						0	0	0
(4) Rob Rapaport Secretary	5	✓						0	0	0
(5) Debbie Stoddard Treasurer	3	✓						0	0	0
(6) Erin Meisner Advocacy Director	3	✓						0	0	0
(7) Maria Rebbecca Education Director	3	✓						0	0	0
(8) Kelly Jones Communications Director	3	✓						0	0	0
(9) April Breen Fundraising Director	3	✓						0	0	0
(10)										
(11)										
(12)										
(13)										
(14)										

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(15)										
(16)										
(17)										
(18)										
(19)										
(20)										
(21)										
(22)										
(23)										
(24)										
(25)										
1b Subtotal								41,200	0	0
c Total from continuation sheets to Part VII, Section A								0	0	0
d Total (add lines 1b and 1c)								41,200	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 **0**

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

Section B. Independent Contractors

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

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

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

Part VIII Statement of RevenueCheck if Schedule O contains a response or note to any line in this Part VIII ☐

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns	1a	0			
	b	Membership dues	1b	0			
	c	Fundraising events	1c	0			
	d	Related organizations	1d	0			
	e	Government grants (contributions)	1e	0			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	204,776			
	g	Noncash contributions included in lines 1a-1f	1g	\$ 0			
	h	Total. Add lines 1a-1f		204,776			
Program Service Revenue				Business Code			
	2a	conference registrations		813219	29,879		
	b	conference income (sponsors & grants)		813219	89,297		
	c	(inc. prior year)					
	d	awareness merchandise sales		813219	10,817		
	e						
	f	All other program service revenue					
g	Total. Add lines 2a-2f		129,993				
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		0			
	4	Income from investment of tax-exempt bond proceeds		0			
	5	Royalties		0			
	6a	Gross rents	(i) Real	0	(ii) Personal	0	
	b	Less: rental expenses		0		0	
	c	Rental income or (loss)		0		0	
	d	Net rental income or (loss)					
	7a	Gross amount from sales of assets other than inventory	(i) Securities	0	(ii) Other	0	
	b	Less: cost or other basis and sales expenses		0		0	
	c	Gain or (loss)		0		0	
	d	Net gain or (loss)					
	8a	Gross income from fundraising events (not including \$ 0 of contributions reported on line 1c). See Part IV, line 18		0			
	b	Less: direct expenses		0			
	c	Net income or (loss) from fundraising events		0			
	9a	Gross income from gaming activities. See Part IV, line 19		0			
	b	Less: direct expenses		0			
	c	Net income or (loss) from gaming activities		0			
10a	Gross sales of inventory, less returns and allowances		0				
b	Less: cost of goods sold		0				
c	Net income or (loss) from sales of inventory		0				
Miscellaneous Revenue				Business Code			
	11a	bonus points back on credit card		813219	696		
	b						
	c						
	d	All other revenue					
e	Total. Add lines 11a-11d		696				
12	Total revenue. See instructions		335,465				

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX ☐**Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.**

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	162,000	162,000		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	19,505	19,505		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	0	0		
4 Benefits paid to or for members	0	0		
5 Compensation of current officers, directors, trustees, and key employees	41,200	31,325	9,875	0
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0	0	0	0
7 Other salaries and wages	0	0	0	0
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0	0	0	0
9 Other employee benefits	0	0	0	0
10 Payroll taxes	3,152	2,397	755	0
11 Fees for services (nonemployees):				
a Management	0	0	0	0
b Legal	0	0	0	0
c Accounting	529	0	529	0
d Lobbying	0	0	0	0
e Professional fundraising services. See Part IV, line 17	0			0
f Investment management fees	0	0	0	0
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)	18,111	18,111	0	0
12 Advertising and promotion	408	408	0	0
13 Office expenses	473	473	0	0
14 Information technology	2,233	337	696	1,200
15 Royalties	0	0	0	0
16 Occupancy	0	0	0	0
17 Travel	13,046	13,046	0	0
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0	0	0	0
19 Conferences, conventions, and meetings	125,940	125,940	0	0
20 Interest	0	0	0	0
21 Payments to affiliates	0	0	0	0
22 Depreciation, depletion, and amortization	0	0	0	0
23 Insurance	1,668	0	1,668	0
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 awareness merch	6,148	6,148	0	0
b print, exhibit	12,454	12,454	0	0
c outreach packets for newly diagnosed	2,750	2,750	0	0
d payroll service fees	1,009	566	443	0
e All other expenses bank fees, postage, training	5,628	1,319	0	4,309
25 Total functional expenses. Add lines 1 through 24e	416,254	396,779	13,966	5,509
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	194,209	1	94,615
	2 Savings and temporary cash investments	0	2	0
	3 Pledges and grants receivable, net	0	3	0
	4 Accounts receivable, net	0	4	0
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0	5	0
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)	0	6	0
	7 Notes and loans receivable, net	0	7	0
	8 Inventories for sale or use	0	8	3,387
	9 Prepaid expenses and deferred charges	0	9	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D 10a			
	b Less: accumulated depreciation 10b	0	10c	0
	11 Investments—publicly traded securities	0	11	0
	12 Investments—other securities. See Part IV, line 11	0	12	0
	13 Investments—program-related. See Part IV, line 11	0	13	0
	14 Intangible assets	0	14	0
	15 Other assets. See Part IV, line 11	0	15	0
	16 Total assets. Add lines 1 through 15 (must equal line 33)	194,209	16	98,002
Liabilities	17 Accounts payable and accrued expenses	(88)	17	(703)
	18 Grants payable	0	18	0
	19 Deferred revenue	0	19	0
	20 Tax-exempt bond liabilities	0	20	0
	21 Escrow or custodial account liability. Complete Part IV of Schedule D	0	21	0
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons	0	22	0
	23 Secured mortgages and notes payable to unrelated third parties	0	23	0
	24 Unsecured notes and loans payable to unrelated third parties	0	24	0
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17–24). Complete Part X of Schedule D	0	25	0
	26 Total liabilities. Add lines 17 through 25	(88)	26	(703)
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	0	27	97,299
	28 Net assets with donor restrictions	0	28	0
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds	0	29	0
	30 Paid-in or capital surplus, or land, building, or equipment fund	0	30	0
	31 Retained earnings, endowment, accumulated income, or other funds	0	31	0
	32 Total net assets or fund balances	194,121	32	97,299
33 Total liabilities and net assets/fund balances		194,209	33	98,002

Part XI Reconciliation of Net AssetsCheck 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	335,465
2	Total expenses (must equal Part IX, column (A), line 25)	2	416,254
3	Revenue less expenses. Subtract line 2 from line 1	3	(80,789)
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	194,121
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	(16,033)
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	97,299

Part XII Financial Statements and ReportingCheck 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: ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	✓	
b Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		✓
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? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	✓	
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		✓
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 .		

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ.

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

OMB No 1545-0047

2019

**Open to Public
Inspection**

Name of the organization

Glut1 Deficiency Foundation, Inc.

Employer identification number

45-2190535

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 or 990-EZ).)
- 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)(vii)**. (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 in 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 0
- 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		
(A) none						
(B)						
(C)						
(D)						
(E)						
Total						

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	165,939	165,015	141,440	187,578	204,776	864,748
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf	0	0	0	0	0	0
3 The value of services or facilities furnished by a governmental unit to the organization without charge	0	0	0	0	0	0
4 Total. Add lines 1 through 3	165,939	165,015	141,440	187,578	204,776	864,748
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4						864,748

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
7 Amounts from line 4	165,939	165,015	141,440	187,578	204,776	864,748
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	0	0	0	0	0	0
9 Net income from unrelated business activities, whether or not the business is regularly carried on	0	0	0	0	0	0
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)	0	0	0	0	0	0
11 Total support. Add lines 7 through 10						864,748
12 Gross receipts from related activities, etc. (see instructions)					12	130,869
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f))	14	100 %
15 Public support percentage from 2018 Schedule A, Part II, line 14	15	100 %
16a 33¹/₃% support test—2019. 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 33¹/₃% support test—2018. 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—2019. 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—2018. 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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
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						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five 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

15 Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2018 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2019 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2018 Schedule A, Part III, line 17	18	%
19a 33 1/3% support tests—2019. 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—2018. 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 in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <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>		
2 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>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
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>		
c 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>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
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>		
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <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>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) 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 Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>		
7 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 or 990-EZ).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined in 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>		
c Did a disqualified person (as defined in 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>		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer 10b below.</i>		
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
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?		
b A family member of a person described in (a) above?		
c A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI .		

Section B. Type I Supporting Organizations

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

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

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

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).		
a ☐ The organization satisfied the Activities Test. Complete line 2 below.		
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.		
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
2 Activities Test. Answer (a) and (b) below.		
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.		
b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.		
3 Parent of Supported Organizations. Answer (a) and (b) below.		
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? Provide details in Part VI .		
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.		

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

- 1** ☐ Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A—Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3.	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8		
Section B—Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):			
a Average monthly value of securities	1a		
b Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI):			
2 Acquisition indebtedness applicable to non-exempt-use assets	2		
3 Subtract line 2 from line 1d.	3		
4 Cash deemed held for exempt use. Enter 1-1/2% 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 .035.	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		
Section C—Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2 Enter 85% of line 1.	2		
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4 Enter greater of line 2 or line 3.	4		
5 Income tax imposed in prior year	5		
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		
7 ☐ 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)

Section D—Distributions		Current Year	
1	Amounts paid to supported organizations to accomplish exempt purposes		
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity		
3	Administrative expenses paid to accomplish exempt purposes of supported organizations		
4	Amounts paid to acquire exempt-use assets		
5	Qualified set-aside amounts (prior IRS approval required)		
6	Other distributions (describe in Part VI). See instructions.		
7	Total annual distributions. Add lines 1 through 6.		
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.		
9	Distributable amount for 2019 from Section C, line 6		
10	Line 8 amount divided by line 9 amount		

Section E—Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1 Distributable amount for 2019 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2019 (reasonable cause required—explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2019			
a From 2014			
b From 2015			
c From 2016			
d From 2017			
e From 2018			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2019 distributable amount			
i Carryover from 2014 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2019 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2019 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2019, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2020. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2015			
b Excess from 2016			
c Excess from 2017			
d Excess from 2018			
e Excess from 2019			

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

Area with horizontal dashed lines for supplemental information.

SCHEDULE I
(Form 990)

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.

OMB No 1545-0047

2019

Open to Public
Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization

Glut1 Deficiency Foundation, Inc

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

Employer identification number

45-2190535

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 non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
(1) Columbia Univ Med Center 622 W 113th Str MC 4524 NY, NY	13-5598093		25,000				research grant
(2) Texas Tech University 2625 Memorial Cir. Lubbock, TX	75-6002622		20,000				research grant
(3) Columbia Univ Med Center 622 W 113th Str MC 4524 NY, NY	13-5598093		35,000				research grant
(4) Univ Texas Southwestern 5323 Harry Hines Dallas, TX 75390	75-6002868		42,000				research grant
(5) Univ Texas Southwestern 5323 Harry Hines Dallas, TX 75390	75-6002868		40,000				research grant
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 0
- 3 Enter total number of other organizations listed in the line 1 table 5

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

Cat. No 50055P

Schedule I (Form 990) (2019)

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

	(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
1	Conference travel stipend for adult patients	39	19,505	0		
2						
3						
4						
5						
6						
7						

Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

Part II: The Glut1 Deficiency Foundation provides grants to institutional researchers who are conducting scientific research for better understanding and better treatments of

Glut1 Deficiency. Grants are awarded by the Board of Directors with input from our Scientific Advisory Board through a review and scoring process. Half of the one year

grant awards are delivered at start of the grant, and the other half delivered at the mid-point. Interim reports are due at the midpoint before remaining funds are distributed and a final report

is due at the conclusion of the grant period with the expectation to publicly share the work in a publication. Progress is monitored by the Board of Directors and Executive Director.

Part III: The Glut1 Deficiency Foundation awarded travel stipends for adult patients as part of a special patient engagement conference grant from PCORI. All adult patients who

attended the conference were eligible for the grant, which were \$500 each. We awarded 39 travel stipends and also incurred a transaction fee of \$5 for one of the fund transfers.

SCHEDULE L
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Transactions With Interested Persons

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c, or Form 990-EZ, Part V, line 38a or 40b.**
▶ **Attach to Form 990 or Form 990-EZ.**
▶ **Go to www.irs.gov/Form990 for instructions and the latest information.**

OMB No 1545-0047

2019

Open To Public Inspection

Name of the organization

Glut1 Deficiency Foundation, Inc.

Employer identification number

45-2190535

Part I

Excess Benefit Transactions (section 501(c)(3), section 501(c)(4), and section 501(c)(29) organizations only).

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b.

1	(a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
				Yes	No
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					

2 Enter the amount of tax incurred by the organization managers or disqualified persons during the year under section 4958. ▶ \$

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ▶ \$

Part II

Loans to and/or From Interested Persons.

Complete if the organization answered "Yes" on Form 990-EZ, Part V, line 38a or Form 990, Part IV, line 26; or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22.

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?		(i) Written agreement?	
			To	From			Yes	No	Yes	No	Yes	No
(1)												
(2)												
(3)												
(4)												
(5)												
(6)												
(7)												
(8)												
(9)												
(10)												
Total ▶						\$						

Part III

Grants or Assistance Benefiting Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance
(1) Tessa Breen	daughter of board member	\$500	adult patient travel stipend	part of PCORI grant
(2) JR Rapaport	son of board member	\$500	adult patient travel stipend	part of PCORI grant
(3) Macie Steele	daughter of Executive Director	\$500	adult patient travel stipend	part of PCORI grant
(4) Dalton Stoddard	son of board member	\$500	adult patient travel stipend	part of PCORI grant
(5)				*all adult patient
(6)				in-person conference
(7)				attendees received a \$500
(8)				travel stipend to attend
(9)				conference (39 total)
(10)				

Part IV Business Transactions Involving Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					

Part V Supplemental Information.

Provide additional information for responses to questions on Schedule L (see instructions).

Part III: As part of a PCORI funded project to explore adult experiences in Glut1 Deficiency, all adult patients were eligible for a \$500

travel stipend to attend the July 2019 conference in person. The Foundation distributed 39 travel stipends in total, including one to adult

children of board members April Breen, Rob Rapaport, Debbie Stoddard, and Executive Director Glenna Steele.

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

► Attach to Form 990 or 990-EZ.

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

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2019

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Name of the organization

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Part VI: Section B: Policies

11a: Process to review 990

All board members are emailed a copy of the completed 990 and given opportunity to review before filing.

12c: Monitor and enforce compliance for conflict of interest policy

The conflict of interest policy is reviewed annually, discussed at annual board meetings, and board members sign a disclosure statement each year. There are ongoing discussions about potential conflicts, and board members have the opportunity to recuse themselves from any issues where a conflict may exist. Other board members may raise conflict concerns and outcomes are decided by the board.

15a: Compensation

Compensation for Executive Director was first determined by a committee who researched comparability data, created a job description, and instituted an annual review process, then board voted and approved. Similar process will be followed for any additional employees.

Part VI: Section C: Disclosures

19: Governing documents, conflict of interest policy, tax returns, and financial information are available to the public on our website and upon request

Part XI: Line 9: Other changes in net assets or fund balances

Reviewed financial statements reflect changes in net assets to appropriately reflect corresponding journal entries for (increase) decrease in operating assets through inventory and prepaid expenses and an increase (decrease) in operating liabilities through accounts payable and deferred revenue.

Part XII: Line 1

The Glut1 Deficiency Foundation adopted an accrual accounting method at the recommendation of our accounting consultants based on review of practices and financial statements.

Name of the organization

Employer identification number

Area with horizontal dashed lines for supplemental information.