

990
Form
Department of the Treasury
Internal Revenue Service

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.

OMB No. 1545-0047
2019
 Open to Public Inspection

A For the 2019 calendar year, or tax year beginning 01-01-2019, and ending 12-31-2019

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 CONGENITAL HYPERINSULINISM INTERNATIONAL		D Employer identification number 20-3068945
	Doing business as		E Telephone number (973) 566-0334
	Number and street (or P.O. box if mail is not delivered to street address) PO BOX 135	Room/suite	G Gross receipts \$ 512,912
	City or town, state or province, country, and ZIP or foreign postal code GLEN RIDGE, NJ 07028		
F Name and address of principal officer: PO BOX 135 GLEN RIDGE, NJ 07028		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) H(c) Group exemption number ▶	
I 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			
J Website: ▶ www.congenitalhi.org			
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: 2006	M State of legal domicile: NM

Part I Summary

1 Briefly describe the organization's mission or most significant activities:
 Congenital Hyperinsulinism International (CHI) is the leading patient organization dedicated to improving the lives of people with hyperinsulinism (HI). HI is a life-threatening disorder that causes dangerously low blood sugar levels due to the over-production of insulin.

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	9
4 Number of independent voting members of the governing body (Part VI, line 1b)	4	9
5 Total number of individuals employed in calendar year 2019 (Part V, line 2a)	5	3
6 Total number of volunteers (estimate if necessary)	6	138
7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
7b Net unrelated business taxable income from Form 990-T, line 39	7b	

	Prior Year	Current Year
8 Contributions and grants (Part VIII, line 1h)	270,089	270,090
9 Program service revenue (Part VIII, line 2g)	110,485	224,080
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)		0
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-24,995	-27,481
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	355,579	466,689
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	75,481	137,021
14 Benefits paid to or for members (Part IX, column (A), line 4)		0
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	178,877	190,140
16a Professional fundraising fees (Part IX, column (A), line 11e)		0
b Total fundraising expenses (Part IX, column (D), line 25) ▶ 30,825		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	127,693	167,340
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	382,051	494,501
19 Revenue less expenses. Subtract line 18 from line 12	-26,472	-27,812
	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	618,444	593,116
21 Total liabilities (Part X, line 26)	8,234	10,718
22 Net assets or fund balances. Subtract line 21 from line 20	610,210	582,398

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	Signature of officer	2020-09-28
	MASON SMITH Treasurer	Date
	Type or print name and title	

Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check <input checked="" type="checkbox"/> if self-employed	PTIN P00847064
	Firm's name ▶ MAUREEN A LEIDL CPA			Firm's EIN ▶ 27-2133606	
	Firm's address ▶ 223 LORRAINE AVE MONTCLAIR, NJ 07043			Phone no. (973) 783-2000	

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

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission:

CHI is dedicated to improving the lives of babies, children, and adults affected by HI. CHI provides education, information and support to families of diagnosed children and adults living with the condition. CHI works to promote knowledge and awareness of the disorder as it leads to timely diagnosis and decreases death and brain damage, better care and better neurological outcomes. CHI supports research and development for a better understanding of the condition, leading to a better quality of life, better treatments and management of the condition, and ultimately, a cure.

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 \$ **211,744** including grants of \$) (Revenue \$)

CHI supports research and development to better understand, treat, manage and hopefully cure HI. CHI shares the patient perspective with researchers, members of the biopharmaceutical industry to accelerate the development of patient-centered treatments. CHI is part of the Million Dollar Bike Ride grant program with the University of Pennsylvania's Center for Orphan Diseases; a pilot research grant is offered each year for an innovative, preclinical or clinical study with the potential to lead to a better HI treatment, a cure for HI, or improvement in the quality of life for those affected by HI. CHI also administers a one-time hyperinsulinism hyperammonemia(HIHA) pilot grant for an innovative, preclinical study that has the potential to lead to a better HIHA treatment, a cure for HIHA, or improved quality of life to those affected by HIHA. CHI conducts the HI Global Registry (HIGR) research project. HIGR provides a convenient online platform for the HI patient community to share their experiences of living with HI. By participating in the HI Global Registry, the patient community helps themselves and researchers better understand HI to advance better treatments, a potential cure, and more timely and accurate diagnoses.

4b (Code:) (Expenses \$ **142,740** including grants of \$) (Revenue \$)

CHI advocates on behalf of families all over the world for access to quality treatment, medication, and supplies. CHI provides opportunities for affected families to emotionally support each other because the home care medical management of HI is often complicated and difficult. CHI offers online forums, and CHI staff and volunteers are available by telephone and in-person for support. CHI establishes funds at hospitals to support families from out of town who must travel to centers of excellence for patient care. CHI covers the cost of genetic testing for HI for any patient suspected of having the disease who otherwise cannot afford genetic testing. The testing is conducted by a leading genetics lab at the University of Exeter in the UK.

4c (Code:) (Expenses \$ **84,347** including grants of \$) (Revenue \$)

CHI increases awareness of HI in order to improve timely diagnosis among the public and medical personnel who have a direct opportunity to detect it, to decrease adverse neurological outcomes and death. To that end, CHI spreads awareness of HI with ongoing campaigns on social media, the CHI website and blog, CHI posters in 21 languages, CHI brochures, through direct mail and email, and at meetings and conferences. CHI provides educational resources and holds onferences and meetings on HI for patients, families, medical professionals, school personnel, and rare disease industry members.

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

4e **Total program service expenses** **438,831**

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1 through 21 regarding organizational requirements for various schedules (A through H).

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 22 through 38 regarding tax-exempt bond issues, excess benefit transactions, and related party transactions.

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and gaming winnings.

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

Table with 16 main sections (2a-16) and sub-questions (a-h). Includes questions about employee reporting, federal employment tax returns, unrelated business gross income, foreign country accounts, prohibited tax shelter transactions, annual gross receipts, deductible contributions, sponsoring organizations, and charitable trusts. Includes input fields for numbers and checkboxes for Yes/No.

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in 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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members... 2 Did any officer, director, trustee... 3 Did the organization delegate control... 4 Did the organization make any significant changes... 5 Did the organization become aware... 6 Did the organization have members... 7a Did the organization have members... 7b Are any governance decisions... 8 Did the organization contemporaneously document... 8a The governing body? 8b Each committee... 9 Is there any officer, director, trustee...

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... 10b If "Yes," did the organization have written policies... 11a Has the organization provided a complete copy... 11b Describe in Schedule O the process... 12a Did the organization have a written conflict... 12b Were officers, directors, or trustees... 12c Did the organization regularly and consistently... 13 Did the organization have a written whistleblower... 14 Did the organization have a written document... 15 Did the process for determining compensation... 15a The organization's CEO... 15b Other officers or key employees... 16a Did the organization invest in, contribute assets... 16b If "Yes," did the organization follow a written policy...

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed CA, CO, CT, FL, IL, MA, MD, NJ, NM, NY, PA, VA
18 Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
19 Describe in 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: JULIE RASKIN 117 WATCHUNG AVENUE REAR MONTCLAIR, NJ 07042 (973) 544-8372

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

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

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

- List all of the organization's **current** key employees, if any. See 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, or 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) JULIE RASKIN Executive Dir.	40.00 0.00	X		X				75,000	0	0
(2) SHEILA BOSE Vice President	1.00 0.00	X		X				0	0	0
(3) MATTHEW M HOPKINS Director	1.00 0.00	X						0	0	0
(4) JEFFREY R HART Director	1.00 0.00	X						0	0	0
(5) DAVELYN HOOD President	10.00 0.00	X		X				0	0	0
(6) ISABEL CALDERON Director	5.00 0.00	X						0	0	0
(7) MARGARET MAHER Secretary	1.00 0.00	X		X				0	0	0
(8) MASON SMITH Treasurer	2.00 0.00	X		X				0	0	0
(9) PAM WILLIAMS Director	1.00 0.00	X						0	0	0
(10) JULIE SHELDON Director	1.00 0.00	X						0	0	0

Part VIII Statement of Revenue

Check 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				
	b Membership dues	1b				
	c Fundraising events	1c	149,572			
	d Related organizations	1d				
	e Government grants (contributions)	1e				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	120,518			
	g Noncash contributions included in lines 1a - 1f:\$	1g				
	h Total. Add lines 1a-1f		270,090			
Program Service Revenue	2a CONFERENCES	Business Code	88,500			88,500
	b RESEARCH		135,580			135,580
	c					
	d					
	e					
	f All other program service revenue.					
	g Total. Add lines 2a-2f.		224,080			
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				
		(ii) Personal				
		6b Less: rental expenses				
		6c Rental income or (loss)		0		
	7a Gross amount from sales of assets other than inventory	(i) Securities				
		(ii) Other				
		7b Less: cost or other basis and sales expenses				
		7c Gain or (loss)		0		
	8a Gross income from fundraising events (not including \$ 149,572 of contributions reported on line 1c). See Part IV, line 18	8a	18,285			
	b Less: direct expenses	8b	46,223			
	c Net income or (loss) from fundraising events		-27,938			
	9a Gross income from gaming activities. See Part IV, line 19	9a				
b Less: direct expenses		9b				
c Net income or (loss) from gaming activities			0			
10a Gross sales of inventory, less returns and allowances	10a					
	b Less: cost of goods sold	10b				
	c Net income or (loss) from sales of inventory		0			
Miscellaneous Revenue	Business Code					
11a Miscellaneous	900099	457			457	
b						
c						
d All other revenue						
e Total. Add lines 11a-11d		457				
12 Total revenue. See instructions		466,689			224,537	

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	81,281	81,281		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	0			
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	55,740	55,740		
4 Benefits paid to or for members	0			
5 Compensation of current officers, directors, trustees, and key employees	75,000	63,750	3,750	7,500
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			
7 Other salaries and wages	99,886	86,564	6,662	6,660
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	0			
9 Other employee benefits	0			
10 Payroll taxes	15,254	13,111	923	1,220
11 Fees for services (non-employees):				
a Management	0			
b Legal	0			
c Accounting	16,317	3,072	10,173	3,072
d Lobbying	0			
e Professional fundraising services. See Part IV, line 17	0			
f Investment management fees	0			
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	0			
12 Advertising and promotion	0			
13 Office expenses	1,432	942	235	255
14 Information technology	0			
15 Royalties	0			
16 Occupancy	7,522	5,973	657	892
17 Travel	4,154	4,154		
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19 Conferences, conventions, and meetings	82,698	82,698		
20 Interest	0			
21 Payments to affiliates	0			
22 Depreciation, depletion, and amortization	3,333	3,333		
23 Insurance	346	223	59	64
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a TELECOMMUNICATION & TECHNOLOGY	37,082	25,821	1,743	9,518
b PROGRAM COSTS AND MATERIALS	7,550	7,550		
c PRINTING, COPYING AND POSTAGE	2,660	1,596	532	532
d DUES & SUBSCRIPTIONS	2,245	2,022	111	112
e All other expenses	2,001	1,001		1,000
25 Total functional expenses. Add lines 1 through 24e	494,501	438,831	24,845	30,825
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year
Assets	1 Cash-non-interest-bearing	559,833	1	563,598
	2 Savings and temporary cash investments		2	0
	3 Pledges and grants receivable, net	50,000	3	21,487
	4 Accounts receivable, net		4	0
	5 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		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)		6	0
	7 Notes and loans receivable, net		7	0
	8 Inventories for sale or use		8	0
	9 Prepaid expenses and deferred charges		9	2,753
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D 10a			
	b Less: accumulated depreciation 10b		10c	0
	11 Investments—publicly traded securities		11	0
	12 Investments—other securities. See Part IV, line 11		12	0
	13 Investments—program-related. See Part IV, line 11		13	0
	14 Intangible assets		14	0
	15 Other assets. See Part IV, line 11	8,611	15	5,278
16 Total assets: Add lines 1 through 15 (must equal line 34)	618,444	16	593,116	
Liabilities	17 Accounts payable and accrued expenses	8,234	17	10,718
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	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		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	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		25	
	26 Total liabilities. Add lines 17 through 25	8,234	26	10,718
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	535,594	27	532,398
	28 Net assets with donor restrictions	74,616	28	50,000
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	610,210	32	582,398
33 Total liabilities and net assets/fund balances	618,444	33	593,116	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	466,689
2	Total expenses (must equal Part IX, column (A), line 25)	2	494,501
3	Revenue less expenses. Subtract line 2 from line 1	3	-27,812
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	610,210
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 in Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (A))	10	582,398

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
2b	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: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
2c	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 in Schedule O.	Yes	
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?		No
3b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.		

Additional Data

Return to Form

Software ID: 19009920

Software Version: 2019v5.0

Form 990, Special Condition Description:

Special Condition Description

SCHEDULE A
(Form 990 or 990EZ)

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
CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number
20-3068945

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)(vi)**. (Complete Part II.)
- 9 An agricultural research organization described in **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 _____
 - 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		
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 failed 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 grant.") . . .	224,417	290,221	221,840	235,590	345,058	1,317,126
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0
3 The value of services or facilities furnished by a governmental unit to the organization without charge..						0
4 Total. Add lines 1 through 3	224,417	290,221	221,840	235,590	345,058	1,317,126
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) . . .						48,348
6 Public support. Subtract line 5 from line 4.						1,268,778

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.	224,417	290,221	221,840	235,590	345,058	1,317,126
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						0
9 Net income from unrelated business activities, whether or not the business is regularly carried on						0
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.).						0
11 Total support. Add lines 7 through 10						1,317,126

12 Gross receipts from related activities, etc. (see instructions) **12** _____

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	96.330 %
15 Public support percentage for 2018 Schedule A, Part II, line 14	15	93.750 %

16a 33 1/3% 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 33 1/3% 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. <input type="checkbox"/>						

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 <input type="checkbox"/>		
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 <input type="checkbox"/>		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions <input type="checkbox"/>		

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of 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? 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.		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer (b) and (c) below.		
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)? If "Yes," describe in Part VI when and how the organization made the determination.		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? 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.		
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)? 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.		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? 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).		
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? If "Yes," provide detail in Part VI .		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (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? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
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))? If "Yes," provide detail in Part VI .		
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? If "Yes," provide detail in Part VI .		
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? If "Yes," provide detail in Part VI .		
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)? If "Yes," answer line 10b below.		
b	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).		

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? <i>If "Yes" to a, b, or c, provide detail in Part VI.</i>		

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? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
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? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

		Yes	No
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)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

		Yes	No
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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions):		
a	<input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c	<input type="checkbox"/> 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? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
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? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
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? <i>Provide details in Part VI.</i>		
b	Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

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

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

Section A - Adjusted Net Income

(A) Prior Year

(B) Current Year
(optional)

1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 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):	1		
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. If the amount is greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. If the amount is 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).

Facts And Circumstances Test

Return Reference	Explanation

Additional Data

Return to Form

Software ID: 19009920

Software Version: 2019v5.0

Schedule B

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

OMB No. 1545-0047

Attach to Form 990, 990-EZ, or 990-PF. Go to www.irs.gov/Form990 for the latest information.

2019

Name of the organization CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number

20-3068945

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

- 501(c)() (enter number) organization
4947(a)(1) nonexempt charitable trust not treated as a private foundation
527 political organization

Form 990-PF

- 501(c)(3) exempt private foundation
4947(a)(1) nonexempt charitable trust treated as a private foundation
501(c)(3) taxable private foundation

Check if your organization is covered by the General Rule or a Special Rule.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

- For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or other property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

- For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000 or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.
For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.
For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year. \$

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it must answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization
CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number
20-3068945

Part I
Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
RESTRICTED		\$ RESTRICTED	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)

Name of organization
 CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number
 20-3068945

Part II **Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____

Name of organization CONGENITAL HYPERINSULINISM INTERNATIONAL	Employer identification number 20-3068945
--	--

Part III Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once. See instructions.) ► \$ _____

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____	_____	_____
	_____	_____	_____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____		_____	
_____		_____	

Additional Data

Return to Form

Software ID: 19009920

Software Version: 2019v5.0

SCHEDULE D
(Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

2019

Open to Public Inspection

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

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

Department of the Treasury
Internal Revenue Service

Name of the organization
CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number
20-3068945

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? **Yes** **No**

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? **Yes** **No**

Part II Conservation Easements.

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

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

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

	Held at the End of the Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register	2d

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

4 Number of states where property subject to conservation easement is located ▶ _____

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? **Yes** **No**

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

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

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? **Yes** **No**

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

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

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

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

(ii) Assets included in Form 990, Part X ▶ \$ _____

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:

a Revenue included on Form 990, Part VIII, line 1 ▶ \$ _____

b Assets included in Form 990, Part X ▶ \$ _____

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

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

Part IV Escrow and Custodial Arrangements.

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

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

Part V Endowment Funds.

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶
 - b** Permanent endowment ▶
 - c** Temporarily restricted endowment ▶
- The percentages on lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

- (i)** unrelated organizations
- (ii)** related organizations

	Yes	No
3a(i)		
3a(ii)		
3b		

- b** If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R?
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other				

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c.) . . . ▶

Part VII Investments—Other Securities.

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

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

Part VIII Investments—Program Related.

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

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Column (b) must equal Form 990, Part X, col.(B) line 13.)		

Part IX Other Assets.

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

(a) Description	(b) Book value
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

Part X Other Liabilities.

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 25.)	

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

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

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

1	Total revenue, gains, and other support per audited financial statements		1	466,689
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a		
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	
3	Subtract line 2e from line 1		3	466,689
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1 :			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)		5	466,689

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

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

1	Total expenses and losses per audited financial statements		1	494,501
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	
3	Subtract line 2e from line 1		3	494,501
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)		5	494,501

Part XIII

Supplemental Information

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

Return Reference	Explanation

Additional Data

[Return to Form](#)

Software ID: 19009920

Software Version: 2019v5.0

2019

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SCHEDULE F (Form 990)

Statement of Activities Outside the United States

Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16. Attach to Form 990. Go to www.irs.gov/Form990 for instructions and the latest information.

Department of the Treasury Internal Revenue Service

Name of the organization CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number 20-3068945

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

- 1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants or assistance...
2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
3 Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

Table with 6 columns: (a) Region, (b) Number of offices in the region, (c) Number of employees, agents, and independent contractors in the region, (d) Activities conducted in region (by type), (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region, (f) Total expenditures for and investments in the region. Includes rows for VIENNA, AUSTRIA and a sub-total.

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)				GENETIC TESTING	55,740	Wire			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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

3 Enter total number of other organizations or entities 1

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Part IV Foreign Forms

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

Additional Data

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SCHEDULE G (Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

OMB No. 1545-0047

2019

Open to Public Inspection

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

Attach to Form 990 or Form 990-EZ.

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

Department of the Treasury Internal Revenue Service

Name of the organization CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number

20-3068945

Part I Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- a Mail solicitations, b Internet and email solicitations, c Phone solicitations, d In-person solicitations, e Solicitation of non-government grants, f Solicitation of government grants, g Special fundraising events

2a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes No

b If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

Table with 6 columns: (i) Name and address of individual or entity (fundraiser), (ii) Activity, (iii) Did fundraiser have custody or control of contributions?, (iv) Gross receipts from activity, (v) Amount paid to (or retained by) fundraiser listed in col. (i), (vi) Amount paid to (or retained by) organization. Rows 1-10 and Total.

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

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

Revenue	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
	SUGAR SOIREE (event type)	(event type)	(total number)	(add col. (a) through col. (c))
1 Gross receipts	167,857			167,857
2 Less: Contributions	149,572			149,572
3 Gross income (line 1 minus line 2)	18,285			18,285
Direct Expenses	4 Cash prizes			
	5 Noncash prizes			
	6 Rent/facility costs	40,014		40,014
	7 Food and beverages			
	8 Entertainment			
	9 Other direct expenses	6,209		
10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				46,223
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				-27,938

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

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

9 Enter the state(s) in which the organization conducts gaming activities: _____

a Is the organization licensed to conduct gaming activities in each of these states? Yes No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No

b If "Yes," explain: _____

11 Does the organization conduct gaming activities with nonmembers? Yes No

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No

13 Indicate the percentage of gaming activity conducted in:

a	The organization's facility	13a	%
b	An outside facility	13b	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ -----

Address ▶ -----

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No

b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ _____ and the amount of gaming revenue retained by the third party ▶ \$ _____.

c If "Yes," enter name and address of the third party:

Name ▶ -----

Address ▶ -----

16 Gaming manager information:

Name ▶ -----

Gaming manager compensation ▶ \$ -----

Description of services provided ▶ -----

Director/officer Employee Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Return Reference	Explanation
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Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

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.

▶ Attach to Form 990.

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

OMB No. 1545-0047

2019

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization
CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number
20-3068945

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.

(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 noncash assistance	(h) Purpose of grant or assistance
(1) CHILDRENS HOSPITAL OF PHILA 34TH ST AND CIVIC CENTER BLVD PHILADELPHIA, PA 19104			40,000	0			RESEARCH and SUPPORT
(2) UNIVERSITY OF PENNSYLVANIA 201 OLD MAIN UNIVERSITY PARK, PA 16802			40,000	0			RESEARCH

- 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 2

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)					
(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.

Return Reference	Explanation
Grantmaker's Description of How Grants are Used	<p>The University of Pennsylvania grant: CHI chose to provide a grant in the amount of \$40,000 to The University of Pennsylvania Orphan Disease Center Million Dollar Bike Ride Pilot Grant Program (the Program) for congenital hyperinsulinism research. The Program is the only program of its kind to match funds and manage a research grant for congenital hyperinsulinism with guidance from CHI. The Program provided an additional \$32,014 of funds by providing a one-year grant in the amount of \$72,014 to support research related to congenital hyperinsulinism. All individuals holding a faculty-level appointment at an academic institution or a senior scientific position at a non-profit institution or foundation were eligible to respond to this Request for Applications written by CHI. The grant was made available for an innovative, pre-clinical or clinical study that has the potential to lead to: (1) faster and more accurate diagnoses of congenital hyperinsulinism (HI); (2) better HI treatment; (3) a cure for HI; or (4) quality of life improvement for those affected by HI. This grant is made possible by Team Raring to Go for CHI, and CHI and the University of Pennsylvania. CHI recommends grant reviewers for the process which is overseen by The Orphan Disease Center of the University of Pennsylvania. Children's Hospital of Philadelphia grant: CHI administers a one-time hyperinsulinism hyperammonemia (HIHA) pilot grant for an innovative, preclinical study that has the potential to lead to better HIHA treatment, a cure for HIHA, or improved quality of life to those affected by HIHA. Funds related to this grant are monitored through a reporting process provided on a periodic basis.</p>

Additional Data

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SCHEDULE O
(Form 990 or 990-EZ)

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.

Department of the Treasury

Name of the organization

CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number

20-3068945

Return Reference	Explanation
Form 990, Part VI, Line 11b: Form 990 Review Process	A copy of the Form 990 is provided to the President and Treasurer of the Board of Trustees for review prior to filing.
Form 990, Part VI, Line 12c: Explanation of Monitoring and Enforcement of Conflicts	The President of the Board oversees and monitors the adherence to the Conflict of Interest policy. Board members are required to sign and submit the Conflict of Interest policy forms which are reviewed and maintained by the President.
Form 990, Part VI, Line 15a: Compensation Review & Approval Process - CEO, Top Management	The Executive Committee reviews current comparative salaries based on national online resources and makes the salary determination based on performance, experience and longevity with CHI.
Form 990, Part VI, Line 18: Explanation of Other Means Forms Available For Public Inspection	The Form 990 is made available to the public upon request.
Form 990, Part VI, Line 19: Other Organization Documents Publicly Available	The Form 990 is made available to the public upon request.

Additional Data

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Software Version: 2019v5.0