

Form **990**
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
2020
Open to Public Inspection

A For the 2020 calendar year, or tax year beginning 01-01-2020, and ending 12-31-2020

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

C Name of organization
 CONGENITAL HYPERINSULINISM INTERNATIONAL

D Employer identification number
 20-3068945

Doing business as

Number and street (or P.O. box if mail is not delivered to street address) Room/suite
 PO BOX 135

E Telephone number
 (973) 566-0334

City or town, state or province, country, and ZIP or foreign postal code
 GLEN RIDGE, NJ 07028

G Gross receipts \$ 737,474

F Name and address of principal officer:
 PO BOX 135
 GLEN RIDGE, NJ 07028

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: ▶ www.congenitalhi.org

K Form of organization: Corporation Trust Association 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	10
4 Number of independent voting members of the governing body (Part VI, line 1b)	4	10
5 Total number of individuals employed in calendar year 2020 (Part V, line 2a)	5	3
6 Total number of volunteers (estimate if necessary)	6	131
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)	270,090	475,976
9 Program service revenue (Part VIII, line 2g)	224,080	246,110
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)	-27,481	-14,279
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	466,689	707,807
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	137,021	93,872
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)	190,140	224,860
16a Professional fundraising fees (Part IX, column (A), line 11e)		0
b Total fundraising expenses (Part IX, column (D), line 25) ▶ 40,000		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	167,340	148,965
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	494,501	467,697
19 Revenue less expenses. Subtract line 18 from line 12	-27,812	240,110

	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	593,116	1,097,548
21 Total liabilities (Part X, line 26)	10,718	275,040
22 Net assets or fund balances. Subtract line 21 from line 20	582,398	822,508

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
 Date 2021-08-30

MASON SMITH Treasurer
 Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name Preparer's signature Date

Check 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 congenital hyperinsulinism (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 \$ 177,551 including grants of \$) (Revenue \$)
See Additional Data

4b (Code:) (Expenses \$ 129,636 including grants of \$) (Revenue \$)
See Additional Data

4c (Code:) (Expenses \$ 89,946 including grants of \$) (Revenue \$)
See Additional Data

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

4e Total program service expenses ▶ 397,133

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 1 through 21, with sub-questions a-f for questions 11 and 12. Each row has a corresponding '1' through '21' in the first column of the table grid.

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 organizational reporting, compensation, and tax-exempt status.

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, Form W-2G, and backup withholding rules.

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

<p>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</p>	2a	3		
<p>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)</p>			2b	Yes
<p>3a Did the organization have unrelated business gross income of \$1,000 or more during the year?</p>			3a	No
<p>b If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation in Schedule O</i></p>			3b	
<p>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)?</p>			4a	No
<p>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).</p>				
<p>5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?</p>			5a	No
<p>b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?</p>			5b	No
<p>c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?</p>			5c	
<p>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?</p>			6a	Yes
<p>b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?</p>			6b	Yes
7 Organizations that may receive deductible contributions under section 170(c).				
<p>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?</p>			7a	Yes
<p>b If "Yes," did the organization notify the donor of the value of the goods or services provided?</p>			7b	Yes
<p>c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?</p>			7c	No
<p>d If "Yes," indicate the number of Forms 8282 filed during the year</p>	7d	0		
<p>e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?</p>			7e	No
<p>f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?</p>			7f	No
<p>g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?</p>			7g	No
<p>h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?</p>			7h	No
<p>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?</p>			8	
9 Sponsoring organizations maintaining donor advised funds.				
<p>a Did the sponsoring organization make any taxable distributions under section 4966?</p>			9a	
<p>b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?</p>			9b	
10 Section 501(c)(7) organizations. Enter:				
<p>a Initiation fees and capital contributions included on Part VIII, line 12</p>	10a			
<p>b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities</p>	10b			
11 Section 501(c)(12) organizations. Enter:				
<p>a Gross income from members or shareholders</p>	11a			
<p>b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)</p>	11b			
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?				
<p>b If "Yes," enter the amount of tax-exempt interest received or accrued during the year.</p>	12b			
13 Section 501(c)(29) qualified nonprofit health insurance issuers.				
<p>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.</p>			13a	
<p>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</p>	13b			
<p>c Enter the amount of reserves on hand</p>	13c			
<p>14a Did the organization receive any payments for indoor tanning services during the tax year?</p>			14a	No
<p>b If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation in Schedule O</i></p>			14b	
<p>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.</p>			15	No
<p>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.</p>			16	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 5 columns: Question, 1a, 1b, Yes, No. Rows include questions about voting members, family relationships, management control, and governance decisions.

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

Table with 5 columns: Question, Yes, No. Rows include questions about local chapters, written policies, conflict of interest, whistleblower, and document retention policies.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed
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.
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:

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				83,010	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) TURAYA BRYANT KAMAU Director	1.00 0.00	X						0	0	0
(5) ERIN GREAVES Director	1.00 0.00	X						0	0	0
(6) DAVELYN HOOD President	10.00 0.00	X		X				0	0	0
(7) DINA TALLIS Director	1.00 0.00	X						0	0	0
(8) MARGARET MAHER Secretary	1.00 0.00	X		X				0	0	0
(9) MASON SMITH Treasurer	2.00 0.00	X		X				0	0	0
(10) PAM WILLIAMS Director	1.00 0.00	X						0	0	0
(11) 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	161,870				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	314,106				
	g Noncash contributions included in lines 1a - 1f:\$	1g					
	h Total. Add lines 1a-1f			475,976			
Program Service Revenue	2a CONFERENCES	Business Code		102,720		102,720	
	b RESEARCH			143,390		143,390	
	c						
	d						
	e						
	f All other program service revenue						
	g Total. Add lines 2a-2f.		246,110				
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)					
	d Net 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)					
	d Net gain or (loss)			0			
	8a Gross income from fundraising events (not including \$ 161,870 of contributions reported on line 1c). See Part IV, line 18						
		8b Less: direct expenses		15,388			
		c Net income or (loss) from fundraising events			-14,279		
	9a Gross income from gaming activities. See Part IV, line 19						
9b Less: direct expenses							
c Net income or (loss) from gaming activities				0			
10a Gross sales of inventory, less returns and allowances							
	10b Less: cost of goods sold						
	c Net income or (loss) from sales of inventory			0			
11a Miscellaneous Revenue	Business Code						
	b						
	c						
	d All other revenue						
	e Total. Add lines 11a-11d			0			
12 Total revenue. See instructions			707,807				
						246,110	

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	55,000	55,000		
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.	38,872	38,872		
4 Benefits paid to or for members	0			
5 Compensation of current officers, directors, trustees, and key employees	83,010	70,559	4,151	8,300
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	123,951	103,837	9,108	11,006
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions)	0			
9 Other employee benefits	0			
10 Payroll taxes	17,899	15,082	1,148	1,669
11 Fees for services (non-employees):				
a Management	0			
b Legal	0			
c Accounting	16,471	2,967	10,538	2,966
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)	36,808	27,606		9,202
12 Advertising and promotion	0			
13 Office expenses	4,055	1,851	1,062	1,142
14 Information technology	0			
15 Royalties	0			
16 Occupancy	7,634	6,005	704	925
17 Travel	12,064	12,064		
18 Payments of travel or entertainment expenses for any federal, state, or local public officials	0			
19 Conferences, conventions, and meetings	38,262	38,262		
20 Interest	0			
21 Payments to affiliates	0			
22 Depreciation, depletion, and amortization	3,334	3,334		
23 Insurance	3,054	1,329	854	871
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 PROGRAM COSTS AND MATERIALS	13,907	13,907		
b TELECOMMUNICATION & TECHNOLOGY	9,161	3,902	2,490	2,769
c DUES & SUBSCRIPTIONS	1,656	1,490	83	83
d BANK FEES	1,281	640		641
e All other expenses	1,278	426	426	426
25 Total functional expenses. Add lines 1 through 24e	467,697	397,133	30,564	40,000
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	563,598	1	1,060,523
	2 Savings and temporary cash investments		2	0
	3 Pledges and grants receivable, net	21,487	3	21,865
	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	2,753	9	13,216
	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	5,278	15	1,944
16 Total assets. Add lines 1 through 15 (must equal line 33)	593,116	16	1,097,548	
Liabilities	17 Accounts payable and accrued expenses	10,718	17	10,715
	18 Grants payable		18	
	19 Deferred revenue		19	228,550
	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	35,775
	26 Total liabilities. Add lines 17 through 25	10,718	26	275,040
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	532,398	27	787,047
	28 Net assets with donor restrictions	50,000	28	35,461
	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	582,398	32	822,508	
33 Total liabilities and net assets/fund balances	593,116	33	1,097,548	

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	707,807
2	Total expenses (must equal Part IX, column (A), line 25)	2	467,697
3	Revenue less expenses. Subtract line 2 from line 1	3	240,110
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	582,398
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 32, column (B))	10	822,508

Part XII Financial Statements and Reporting

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

- 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 in 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 in Schedule O and describe any steps taken to undergo such audits.

	Yes	No
2a		No
2b	Yes	
2c	Yes	
3a		No
3b		

Additional Data

Software ID: 20011551

Software Version: 2020v4.0

EIN: 20-3068945

Name: CONGENITAL HYPERINSULINISM INTERNATIONAL

Form 990 (2020)

Form 990, Part III, Line 4a:

CHI supports research and development to better understand, treat, manage and hopefully cure HI. CHI shares the patient perspective with researchers and 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 HIGR, the patient community helps themselves and researchers better understand HI to advance better treatments, a potential cure, and more timely and accurate diagnoses. In 2020, CHI launched the Collaborative Research Network, after receiving a Rare As One Grant from the Chan Zuckerberg Initiative to create a prioritized research agenda for the development of faster and more accurate diagnoses, new evidence-based treatments and cures, standardized clinical guidelines, and increased and improved access to treatment, medication, devices, and supplies. This ambitious project includes seven working groups focused on different aspects of the agenda, comprised of 57 leading researchers, clinicians, and patient advocates from 16 countries. In 2020, after receiving a Rare Patient Impact Grant from Global Genes, CHI launched the CHI Centers of Excellence designation application process to recognize multi-disciplinary clinical and research centers in the field of congenital hyperinsulinism. In 2021, six centers were granted the designation. The goals of this program are to make it easier for patient families to access care at leading hospitals, encourage patient-focused standards at the leading hospitals, foster a pipeline of expert clinicians and researchers, and to encourage collaboration among researchers, clinicians, and patient leaders and advocates.

Form 990, Part III, Line 4b:

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, online 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.

Form 990, Part III, Line 4c:

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 conferences and meetings on HI for patients, families, medical professionals, school personnel, and rare disease industry members.

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

2020

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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	290,221	221,840	235,590	345,058	634,893	1,727,602
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	290,221	221,840	235,590	345,058	634,893	1,727,602
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). . .						18,680
6 Public support. Subtract line 5 from line 4.						1,708,922

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7 Amounts from line 4. . .	290,221	221,840	235,590	345,058	634,893	1,727,602
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						1,727,602
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First 5 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

14 Public support percentage for 2020 (line 6, column (f) divided by line 11, column (f))	14	98.920 %
15 Public support percentage for 2019 Schedule A, Part II, line 14	15	96.330 %
16a 33 1/3% support test—2020. 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 <input checked="" type="checkbox"/>		
b 33 1/3% support test—2019. 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 <input type="checkbox"/>		
17a 10%-facts-and-circumstances test—2020. 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 <input type="checkbox"/>		
b 10%-facts-and-circumstances test—2019. 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 <input type="checkbox"/>		
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 <input type="checkbox"/>		

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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(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 5 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 2020 (line 8, column (f) divided by line 13, column (f))	15	
16	Public support percentage from 2019 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2020 (line 10c, column (f) divided by line 13, column (f))	17	
18	Investment income percentage from 2019 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2020. 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—2019. 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 on line 12 of Part I. If you checked box 12a, of Part I, complete Sections A and B. If you checked box 12b, of Part I, complete Sections A and C. If you checked box 12c, of Part I, complete Sections A, D, and E. If you checked box 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 lines 3b and 3c 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 box 12a or 12b in Part I, answer lines 4b and 4c 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 lines 5b and 5c 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 (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 line 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 lines 11b and 11c below, the governing body of a supported organization?		
b	A family member of a person described in 11a above?		
c	A 35% controlled entity of a person described in line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI.</i>		

Section B. Type I Supporting Organizations

		Yes	No
1	Did the officers, 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 line 2 above, 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 lines 2a and 2b 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>	Yes	No
b	Did the activities described in line 2a 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 lines 3a and 3b 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>If "Yes" or "No" 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 (<i>explain in detail in Part VI</i>):		
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 0.015 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 0.035	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	<input type="checkbox"/> 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	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (<i>prior IRS approval required - provide details in Part VI</i>)	5	
6 Other distributions (<i>describe in Part VI</i>). See instructions	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions	8	
9 Distributable amount for 2020 from Section C, line 6	9	
10 Line 8 amount divided by Line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1 Distributable amount for 2020 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2020 (reasonable cause required-- <i>explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2020:			
a From 2015.			
b From 2016.			
c From 2017.			
d From 2018.			
e From 2019.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2020 distributable amount			
i Carryover from 2015 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2020 from Section D, line 7:			
\$			
a Applied to underdistributions of prior years			
b Applied to 2020 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions.			
6 Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, <i>explain in Part VI</i> . See instructions.			
7 Excess distributions carryover to 2021. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2016.			
b Excess from 2017.			
c Excess from 2018.			
d Excess from 2019.			
e Excess from 2020.			

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

SCHEDULE D (Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

2020

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.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows 1-4: Total number at end of year, Aggregate value of contributions to (during year), Aggregate value of grants from (during year), 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?
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?

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).
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.

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

- 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?
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)?
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 FASB 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 FASB 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:
(ii) 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 FASB 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:
Table with columns: Amount, 1c Beginning balance, 1d Additions during the year, 1e Distributions during the year, 1f Ending balance
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.

Table with 5 columns: (a) Current year, (b) Prior year, (c) Two years back, (d) Three years back, (e) Four years back. Rows include: 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 Term 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
b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R?
Table with columns: Yes, No. Rows: 3a(i), 3a(ii), 3b
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.

Table with 4 columns: (a) Cost or other basis (investment), (b) Cost or other basis (other), (c) Accumulated depreciation, (d) Book value. Rows include: 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
(1)		
(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
(1)	
(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) Payroll Proection Prog Refundable Adv	35,775
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 25.)	35,775

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	761,207
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	53,400	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	53,400
3	Subtract line 2e from line 1		3	707,807
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	707,807

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	521,097
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	53,400	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	53,400
3	Subtract line 2e from line 1		3	467,697
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	467,697

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	
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Part XIII **Supplemental Information (continued)**

Return Reference	Explanation
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**SCHEDULE F
(Form 990)**

Department of the Treasury
Internal Revenue Service

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.

OMB No. 1545-0047

2020

Open to Public Inspection

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.

- For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

(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) (such as, fundraising, program services, investments, grants to recipients located in the region)	(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
3a Sub-total					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					

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)
			GENETIC TESTING	38,872	Wire			

- 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 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

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

990 Schedule F, Supplemental Information

Return Reference	Explanation
Part I, Line 2 - Grantmakers Explanation For Monitoring Use of Funds Outside US	The funds for genetic testing are monitored in the following way: Every three months The University of Exeter Medical School in the UK sends a summary report showing the number of patients tested, the countries of referral, the genetic results by gene, the number of mutations identified and the countries from which the patients have been referred. All new research findings which have used samples recruited through this project will be included in confidence in the quarterly report. The reports issued to the referring clinicians for all of the genetic testing undertaken using these funds will clearly state that the testing has been funded by CHI. A CHI patient information sheet together with information on how to join the CHI Registry will accompany each patient report.

SCHEDULE G (Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

OMB No. 1545-0047

2020

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. Includes a Total row at the bottom.

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	177,258			177,258
2 Less: Contributions	161,870			161,870
3 Gross income (line 1 minus line 2)	15,388			15,388
4 Cash prizes				
5 Noncash prizes				
6 Rent/facility costs	25,276			25,276
7 Food and beverages				
8 Entertainment				
9 Other direct expenses	4,391			4,391
10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				29,667
11 Net income summary. Subtract line 10 from line 3, column (d) ▶				-14,279

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			
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**

OMB No. 1545-0047

2020

**Open to Public
Inspection**

Department of the
Treasury
Internal Revenue Service

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.

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) COOK CHILDRENS HOSPITAL 801 7TH AVENUE FORT WORTH, TX 76104			10,000	0			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 \$33,190 of funds by providing a one-year grant in the amount of \$73,190 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>

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.

OMB No. 1545-0047

2020**Open to Public Inspection**

Department of the Treasury

Name of the organization

CONGENITAL HYPERINSULINISM INTERNATIONAL

Employer identification number

20-3068945

990 Schedule O, Supplemental Information

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.

990 Schedule O, Supplemental Information

Return Reference	Explanation
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.

990 Schedule O, Supplemental Information

Return Reference	Explanation
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.

990 Schedule O, Supplemental Information

Return Reference	Explanation
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.

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990, Part VI, Line 19: Other Organization Documents Publicly Available	The Form 990 is made available to the public upon request.