

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

OMB No 1545-0047  
**2018**  
Open to Public Inspection

**A For the 2019 calendar year, or tax year beginning 01-01-2018, and ending 12-31-2018**

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

**C** Name of organization  
CONGENITAL HYPERINSULINISM INTERNATIONAL

Doing business as

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

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

**D** Employer identification number  
20-3068945

**E** Telephone number  
(973) 566-0334

**G** Gross receipts \$ 395,972

**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

<b>3</b> Number of voting members of the governing body (Part VI, line 1a)	9
<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	9
<b>5</b> Total number of individuals employed in calendar year 2018 (Part V, line 2a)	3
<b>6</b> Total number of volunteers (estimate if necessary)	128
<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12	0
<b>7b</b> Net unrelated business taxable income from Form 990-T, line 34	

	Prior Year	Current Year
<b>8</b> Contributions and grants (Part VIII, line 1h)	466,999	270,089
<b>9</b> Program service revenue (Part VIII, line 2g)	37,057	110,485
<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)		0
<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-32,551	-24,995
<b>12</b> Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	471,505	355,579
<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	56,700	75,481
<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)		0
<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	131,232	178,877
<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)		0
<b>b</b> Total fundraising expenses (Part IX, column (D), line 25) ▶24,877		
<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	92,476	127,693
<b>18</b> Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	280,408	382,051
<b>19</b> Revenue less expenses Subtract line 18 from line 12	191,097	-26,472
	Beginning of Current Year	End of Year
<b>20</b> Total assets (Part X, line 16)	653,182	618,444
<b>21</b> Total liabilities (Part X, line 26)	16,500	8,234
<b>22</b> Net assets or fund balances Subtract line 21 from line 20	636,682	610,210

## 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: 2019-10-25

MASON SMITH Treasurer  
Type or print name and title

**Paid Preparer Use Only**

Print/Type preparer's name: MAUREEN A LEIDL CPA  
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 070431948 Phone no: (973) 783-2000

**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 \$ 141,668 including grants of \$ ) (Revenue \$ )  
See Additional Data

**4b** (Code ) (Expenses \$ 110,549 including grants of \$ ) (Revenue \$ )  
See Additional Data

**4c** (Code ) (Expenses \$ 81,303 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** ▶ 333,520

Part IV Checklist of Required Schedules

Table with 3 columns: Question Number, Question Text, Yes, No. Rows include questions 1 through 22 regarding organizational requirements, such as political activities, lobbying, and financial reporting.

**Part IV Checklist of Required Schedules (continued)**

		Yes	No
<b>23</b>	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i> . . . . .	<b>23</b>	No
<b>24a</b>	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> . . . . .	<b>24a</b>	No
<b>b</b>	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? . . . . .	<b>24b</b>	No
<b>c</b>	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? . . . . .	<b>24c</b>	No
<b>d</b>	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? . . . . .	<b>24d</b>	No
<b>25a</b>	<b>Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i> . . . . .	<b>25a</b>	No
<b>b</b>	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i> . . . . .	<b>25b</b>	No
<b>26</b>	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If "Yes," complete Schedule L, Part II</i> . . . . .	<b>26</b>	No
<b>27</b>	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> . . . . .	<b>27</b>	No
<b>28</b>	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)		
<b>a</b>	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> . . . . .	<b>28a</b>	No
<b>b</b>	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> . . . . .	<b>28b</b>	No
<b>c</b>	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i> . . . . .	<b>28c</b>	No
<b>29</b>	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> . . . . .	<b>29</b>	No
<b>30</b>	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i> . . . . .	<b>30</b>	No
<b>31</b>	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> . . . . .	<b>31</b>	No
<b>32</b>	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i> . . . . .	<b>32</b>	No
<b>33</b>	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i> . . . . .	<b>33</b>	No
<b>34</b>	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i> . . . . .	<b>34</b>	No
<b>35a</b>	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	<b>35a</b>	No
<b>b</b>	If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i> . . . . .	<b>35b</b>	
<b>36</b>	<b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i> . . . . .	<b>36</b>	No
<b>37</b>	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	<b>37</b>	No
<b>38</b>	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O . . . . .	<b>38</b>	Yes

**Part V Statements Regarding Other IRS Filings and Tax Compliance**

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

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

<b>2a</b> Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return . . . . .		<b>2a</b>	3		
<b>b</b> If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)		<b>2b</b>		Yes	
<b>3a</b> Did the organization have unrelated business gross income of \$1,000 or more during the year? . . . . .		<b>3a</b>			No
<b>b</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>		<b>3b</b>			No
<b>4a</b> At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? . . . . .		<b>4a</b>			No
<b>b</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)					
<b>5a</b> Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . . . . .		<b>5a</b>			No
<b>b</b> Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		<b>5b</b>			No
<b>c</b> If "Yes," to line 5a or 5b, did the organization file Form 8886-T? . . . . .		<b>5c</b>			
<b>6a</b> Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? . . . . .		<b>6a</b>		Yes	
<b>b</b> If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? . . . . .		<b>6b</b>		Yes	
<b>7 Organizations that may receive deductible contributions under section 170(c).</b>					
<b>a</b> Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor? . . . . .		<b>7a</b>		Yes	
<b>b</b> If "Yes," did the organization notify the donor of the value of the goods or services provided? . . . . .		<b>7b</b>		Yes	
<b>c</b> Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? . . . . .		<b>7c</b>			No
<b>d</b> If "Yes," indicate the number of Forms 8282 filed during the year . . . . .		<b>7d</b>			0
<b>e</b> Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		<b>7e</b>			No
<b>f</b> Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . . . .		<b>7f</b>			No
<b>g</b> If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? . . . . .		<b>7g</b>			No
<b>h</b> If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? . . . . .		<b>7h</b>			No
<b>8 Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year? . . . . .		<b>8</b>			No
<b>9a</b> Did the sponsoring organization make any taxable distributions under section 4966? . . . . .		<b>9a</b>			No
<b>b</b> Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . . . .		<b>9b</b>			No
<b>10 Section 501(c)(7) organizations.</b> Enter					
<b>a</b> Initiation fees and capital contributions included on Part VIII, line 12 . . . . .		<b>10a</b>			
<b>b</b> Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		<b>10b</b>			
<b>11 Section 501(c)(12) organizations.</b> Enter					
<b>a</b> Gross income from members or shareholders . . . . .		<b>11a</b>			
<b>b</b> Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them ) . . . . .		<b>11b</b>			
<b>12a Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?		<b>12a</b>			No
<b>b</b> If "Yes," enter the amount of tax-exempt interest received or accrued during the year		<b>12b</b>			
<b>13 Section 501(c)(29) qualified nonprofit health insurance issuers.</b>					
<b>a</b> Is the organization licensed to issue qualified health plans in more than one state? <b>Note.</b> See the instructions for additional information the organization must report on Schedule O		<b>13a</b>			No
<b>b</b> Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans . . . . .		<b>13b</b>			
<b>c</b> Enter the amount of reserves on hand . . . . .		<b>13c</b>			
<b>14a</b> Did the organization receive any payments for indoor tanning services during the tax year? . . . . .		<b>14a</b>			No
<b>b</b> If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation in Schedule O . . . . .</i>		<b>14b</b>			
<b>15</b> Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N . . . . .		<b>15</b>			No
<b>16</b> Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O . . . . .		<b>16</b>			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 of the governing body at the end of the tax year; 1b Enter the number of voting members included in line 1a, above, who are independent; 2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?; 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?; 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?; 5 Did the organization become aware during the year of a significant diversion of the organization's assets?; 6 Did the organization have members or stockholders?; 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?; 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?; 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following; 8a The governing body?; 8b Each committee with authority to act on behalf of the governing body?; 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O.

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

Section C. Disclosure

- 17 List the States with which a copy of this Form 990 is required to be filed: NJ, NM, NY
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: [ ] Own website, [ ] Another's website, [x] Upon request, [x] Other (explain in Schedule O)
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 VIII Statement of Revenue

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

Table with columns (A) Total revenue, (B) Related or exempt function revenue, (C) Unrelated business revenue, (D) Revenue excluded from tax under sections 512 - 514. Rows include Contributions, Gifts, and Other Similar Amounts; Program Service Revenue; and Other Revenue.

**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

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>				
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21.	50,800	50,800		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22.	0			
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, line 15 and 16.	24,681	24,681		
<b>4</b> Benefits paid to or for members.	0			
<b>5</b> Compensation of current officers, directors, trustees, and key employees.	69,600	62,640	3,480	3,480
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).	0			
<b>7</b> Other salaries and wages.	94,819	83,322	5,749	5,748
<b>8</b> Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions).	0			
<b>9</b> Other employee benefits.	0			
<b>10</b> Payroll taxes.	14,458	12,795	868	795
<b>11</b> Fees for services (non-employees)				
<b>a</b> Management.	0			
<b>b</b> Legal.	0			
<b>c</b> Accounting.	16,042	3,114	9,814	3,114
<b>d</b> Lobbying.	0			
<b>e</b> Professional fundraising services. See Part IV, line 17.	0			
<b>f</b> Investment management fees.	0			
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	0			
<b>12</b> Advertising and promotion.	0			
<b>13</b> Office expenses.	1,967	1,134	419	414
<b>14</b> Information technology.	0			
<b>15</b> Royalties.	0			
<b>16</b> Occupancy.	5,400	4,476	462	462
<b>17</b> Travel.	8,705	8,705		
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials.	0			
<b>19</b> Conferences, conventions, and meetings.	44,445	44,445		
<b>20</b> Interest.	0			
<b>21</b> Payments to affiliates.	0			
<b>22</b> Depreciation, depletion, and amortization.	1,389	1,389		
<b>23</b> Insurance.	2,595	1,320	640	635
<b>24</b> 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.)				
<b>a</b> TELECOMMUNICATION & TECHNOLOGY	34,887	24,008	1,715	9,164
<b>b</b> PROGRAM COSTS AND MATERIALS	7,752	7,752		
<b>c</b> Printing and Publications	1,639	983	328	328
<b>d</b> DUES & SUBSCRIPTIONS	1,142	1,029	56	57
<b>e</b> All other expenses	1,730	927	123	680
<b>25</b> Total functional expenses. Add lines 1 through 24e.	382,051	333,520	23,654	24,877
<b>26</b> 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
<b>Assets</b>	<b>1</b> Cash—non-interest-bearing . . . . .	595,157	<b>1</b>	559,833
	<b>2</b> Savings and temporary cash investments . . . . .		<b>2</b>	0
	<b>3</b> Pledges and grants receivable, net . . . . .	48,025	<b>3</b>	50,000
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	0
	<b>5</b> Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L . . . . .		<b>5</b>	0
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L . . . . .		<b>6</b>	0
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	0
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	0
	<b>9</b> Prepaid expenses and deferred charges . . . . .		<b>9</b>	0
	<b>10a</b> Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	<b>10a</b>		
	<b>b</b> Less accumulated depreciation	<b>10b</b>		<b>10c</b> 0
	<b>11</b> Investments—publicly traded securities . . . . .		<b>11</b>	0
	<b>12</b> Investments—other securities See Part IV, line 11 . . . . .		<b>12</b>	0
	<b>13</b> Investments—program-related See Part IV, line 11 . . . . .		<b>13</b>	0
	<b>14</b> Intangible assets . . . . .		<b>14</b>	0
	<b>15</b> Other assets See Part IV, line 11 . . . . .	10,000	<b>15</b>	8,611
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 34) . . . . .	653,182	<b>16</b>	618,444	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	16,500	<b>17</b>	8,234
	<b>18</b> Grants payable . . . . .		<b>18</b>	
	<b>19</b> Deferred revenue . . . . .		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L . . . . .		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .		<b>24</b>	
	<b>25</b> 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		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 . . . . .	16,500	<b>26</b>	8,234
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.</b>			
	<b>27</b> Unrestricted net assets	562,066	<b>27</b>	535,594
	<b>28</b> Temporarily restricted net assets . . . . .	74,616	<b>28</b>	74,616
	<b>29</b> Permanently restricted net assets		<b>29</b>	
	<b>Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.</b>			
	<b>30</b> Capital stock or trust principal, or current funds . . . . .		<b>30</b>	
	<b>31</b> Paid-in or capital surplus, or land, building or equipment fund . . . . .		<b>31</b>	
	<b>32</b> Retained earnings, endowment, accumulated income, or other funds		<b>32</b>	
<b>33</b> Total net assets or fund balances . . . . .	636,682	<b>33</b>	610,210	
<b>34</b> Total liabilities and net assets/fund balances . . . . .	653,182	<b>34</b>	618,444	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	355,579
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	382,051
<b>3</b>	Revenue less expenses Subtract line 2 from line 1	<b>3</b>	-26,472
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	<b>4</b>	636,682
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain in Schedule O)	<b>9</b>	
<b>10</b>	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	<b>10</b>	610,210

**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
<b>2a</b>		No
<b>2b</b>	Yes	
<b>2c</b>	Yes	
<b>3a</b>		No
<b>3b</b>		

## Additional Data

**Software ID:** 18007218

**Software Version:** 2018v3.1

**EIN:** 20-3068945

**Name:** CONGENITAL HYPERINSULINISM INTERNATIONAL

Form 990 (2018)

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### 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, members of the biopharmaceutical industry to encourage 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 has developed the HI Global Registry which 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 will help themselves and researchers better understand HI to advance better treatments, a potential cure, and more timely and accurate diagnoses. CHI worked on the development of a hyperinsulinism hyperammonemia (HIHA) pilot grant for an innovative, preclinical or clinical 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. Patients with HIHA secrete too much insulin causing hypoglycemia and they have high ammonia levels in their blood. They are at risk for brain damage or death due to prolonged hypoglycemia and frequently have epilepsy and learning disabilities thought to be caused by high ammonia levels.

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### **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 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.

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**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 18 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.

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**SCHEDULE A**  
**(Form 990 or 990-EZ)**

**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](http://www.irs.gov/Form990) for the latest information.

OMB No 1545-0047

**2018**

**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 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		
<b>Total</b>						

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

(Complete only if you checked the box on line 5, 7, 8, or 9 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

	Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>1</b>	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	220,851	224,417	290,221	221,840	235,590	1,192,919
<b>2</b>	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0
<b>3</b>	The value of services or facilities furnished by a governmental unit to the organization without charge						0
<b>4</b>	<b>Total.</b> Add lines 1 through 3	220,851	224,417	290,221	221,840	235,590	1,192,919
<b>5</b>	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)						74,526
<b>6</b>	<b>Public support.</b> Subtract line 5 from line 4						1,118,393

**Section B. Total Support**

	Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>7</b>	Amounts from line 4	220,851	224,417	290,221	221,840	235,590	1,192,919
<b>8</b>	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						0
<b>9</b>	Net income from unrelated business activities, whether or not the business is regularly carried on						0
<b>10</b>	Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						0
<b>11</b>	<b>Total support.</b> Add lines 7 through 10						1,192,919
<b>12</b>	Gross receipts from related activities, etc. (see instructions)					<b>12</b>	

**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**

<b>14</b>	Public support percentage for 2018 (line 6, column (f) divided by line 11, column (f))	<b>14</b>	93.750 %
<b>15</b>	Public support percentage for 2017 Schedule A, Part II, line 14	<b>15</b>	91.700 %

**16a 33 1/3% support test—2018.** 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—2017.** 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—2018.** 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—2017.** 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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>1</b>	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
<b>2</b>	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						
<b>3</b>	Gross receipts from activities that are not an unrelated trade or business under section 513						
<b>4</b>	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
<b>5</b>	The value of services or facilities furnished by a governmental unit to the organization without charge						
<b>6</b>	<b>Total.</b> Add lines 1 through 5						
<b>7a</b>	Amounts included on lines 1, 2, and 3 received from disqualified persons						
<b>b</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						
<b>c</b>	Add lines 7a and 7b						
<b>8</b>	<b>Public support.</b> (Subtract line 7c from line 6)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►		(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>9</b>	Amounts from line 6						
<b>10a</b>	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
<b>b</b>	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
<b>c</b>	Add lines 10a and 10b						
<b>11</b>	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
<b>12</b>	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
<b>13</b>	<b>Total support.</b> (Add lines 9, 10c, 11, and 12.)						

**14 First five years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** ►

**Section C. Computation of Public Support Percentage**

<b>15</b>	Public support percentage for 2018 (line 8, column (f) divided by line 13, column (f))	<b>15</b>	
<b>16</b>	Public support percentage from 2017 Schedule A, Part III, line 15	<b>16</b>	

**Section D. Computation of Investment Income Percentage**

<b>17</b>	Investment income percentage for <b>2018</b> (line 10c, column (f) divided by line 13, column (f))	<b>17</b>	
<b>18</b>	Investment income percentage from <b>2017</b> Schedule A, Part III, line 17	<b>18</b>	

**19a 33 1/3% support tests—2018.** 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—2017.** 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 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
<b>1</b>	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>		
<b>2</b>	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>		
<b>3a</b>	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
<b>b</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>		
<b>c</b>	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>		
<b>4a</b>	Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
<b>b</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>		
<b>c</b>	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>		
<b>5a</b>	Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
<b>b</b>	<b>Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>c</b>	<b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b>	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>		
<b>7</b>	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>		
<b>8</b>	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>		
<b>9a</b>	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>b</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>		
<b>c</b>	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>		
<b>10a</b>	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>b</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
<b>11</b>	Has the organization accepted a gift or contribution from any of the following persons?		
<b>a</b>	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>b</b>	A family member of a person described in (a) above?		
<b>c</b>	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
<b>1</b>	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>		
<b>2</b>	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
<b>1</b>	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
<b>1</b>	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?		
<b>2</b>	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>		
<b>3</b>	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**

<b>1</b>	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year ( <b>see instructions</b> )		
<b>a</b>	<input type="checkbox"/> The organization satisfied the Activities Test. Complete <b>line 2</b> below.		
<b>b</b>	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete <b>line 3</b> below.		
<b>c</b>	<input type="checkbox"/> The organization supported a governmental entity. Describe in <b>Part VI</b> how you supported a government entity (see instructions).		
<b>2</b>	Activities Test <b>Answer (a) and (b) below.</b>		
<b>a</b>	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>b</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>		
<b>3</b>	Parent of Supported Organizations <b>Answer (a) and (b) below.</b>		
<b>a</b>	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>b</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**

- 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

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

<b>Section D - Distributions</b>	<b>Current Year</b>
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	
<b>4</b> Amounts paid to acquire exempt-use assets	
<b>5</b> Qualified set-aside amounts (prior IRS approval required)	
<b>6</b> Other distributions (describe in <b>Part VI</b> ) See instructions	
<b>7 Total annual distributions.</b> Add lines 1 through 6	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ) See instructions	
<b>9</b> Distributable amount for 2018 from Section C, line 6	
<b>10</b> Line 8 amount divided by Line 9 amount	

<b>Section E - Distribution Allocations (see instructions)</b>	<b>(i) Excess Distributions</b>	<b>(ii) Underdistributions Pre-2018</b>	<b>(iii) Distributable Amount for 2018</b>
<b>1</b> Distributable amount for 2018 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2018 (reasonable cause required-- explain in Part VI) See instructions			
<b>3</b> Excess distributions carryover, if any, to 2018			
<b>a</b> From 2013. . . . .			
<b>b</b> From 2014. . . . .			
<b>c</b> From 2015. . . . .			
<b>d</b> From 2016. . . . .			
<b>e</b> From 2017. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2018 distributable amount			
<b>i</b> Carryover from 2013 not applied (see instructions)			
<b>j</b> Remainder Subtract lines 3g, 3h, and 3i from 3f			
<b>4</b> Distributions for 2018 from Section D, line 7			
\$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2018 distributable amount			
<b>c</b> Remainder Subtract lines 4a and 4b from 4			
<b>5</b> Remaining underdistributions for years prior to 2018, if any Subtract lines 3g and 4a from line 2 If the amount is greater than zero, explain in Part VI See instructions			
<b>6</b> Remaining underdistributions for 2018 Subtract lines 3h and 4b from line 1 If the amount is greater than zero, explain in Part VI See instructions			
<b>7 Excess distributions carryover to 2019.</b> Add lines 3j and 4c			
<b>8</b> Breakdown of line 7			
<b>a</b> Excess from 2014. . . . .			
<b>b</b> Excess from 2015. . . . .			
<b>c</b> Excess from 2016. . . . .			
<b>d</b> Excess from 2017. . . . .			
<b>e</b> Excess from 2018. . . . .			

## Additional Data

**Software ID:** 18007218

**Software Version:** 2018v3.1

**EIN:** 20-3068945

**Name:** CONGENITAL HYPERINSULINISM INTERNATIONAL

**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)  
  
Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**  
**► 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](http://www.irs.gov/Form990) for the latest information.**

OMB No 1545-0047  
**2018**  
**Open to Public Inspection**

**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
<b>1</b> Total number at end of year		
<b>2</b> Aggregate value of contributions to (during year)		
<b>3</b> Aggregate value of grants from (during year)		
<b>4</b> Aggregate value at end of year		
<b>5</b> 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?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>6</b> 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?	<input type="checkbox"/> Yes <input type="checkbox"/> 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	
<b>a</b> Total number of conservation easements	<b>2a</b>	
<b>b</b> Total acreage restricted by conservation easements	<b>2b</b>	
<b>c</b> Number of conservation easements on a certified historic structure included in (a)	<b>2c</b>	
<b>d</b> Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register	<b>2d</b>	

**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 |
|--|--------|
| <b>c</b> Beginning balance             |        |
| <b>d</b> Additions during the year     |        |
| <b>e</b> Distributions during the year |        |
| <b>f</b> 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.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
<b>1a</b> Beginning of year balance . . . . .					
<b>b</b> Contributions . . . . .					
<b>c</b> Net investment earnings, gains, and losses					
<b>d</b> Grants or scholarships . . . . .					
<b>e</b> Other expenditures for facilities and programs . . . . .					
<b>f</b> Administrative expenses . . . . .					
<b>g</b> 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
- |  |     |    |
|--|-----|----|
| <b>(i)</b> unrelated organizations . . . . .   | Yes | No |
| <b>(ii)</b> related organizations . . . . .  |     |    |
| <b>b</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
<b>1a</b> Land . . . . .				
<b>b</b> Buildings . . . . .				
<b>c</b> Leasehold improvements				
<b>d</b> Equipment . . . . .				
<b>e</b> 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 _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
<b>Total.</b> (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)		
<b>Total.</b> (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)	
<b>Total.</b> (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)	
<b>Total.</b> (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.

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	355,579
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12			
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>		
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>		
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII ) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	355,579
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line <b>1</b>			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII ) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total revenue Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12 ) . . . . .		<b>5</b>	355,579

**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.

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	382,051
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>		
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>		
<b>c</b>	Other losses . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII ) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	382,051
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line <b>1</b> :			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII ) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total expenses Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18 ) . . . . .		<b>5</b>	382,051

**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](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No 1545-0047  
**2018**  
**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" to Form 990, Part IV, line 14b.

**1 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**

**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 )

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e g , 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 region	(f) Total expenditures for and investments in region
ATHENS, GREECE	0	0	CONFERENCE	EDUCATION	33,079
<b>3a</b> Sub-total					33,079
<b>b</b> Total from continuation sheets to Part I					
<b>c Totals</b> (add lines 3a and 3b)					33,079

**Part II Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" to 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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		UNITED KINGDOM	GENETIC TESTING	24,681	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 will be sent to CHI 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



**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)
		<b>SUGAR SOIREE</b> (event type)	(event type)	(total number)	Total events (add col (a) through col (c))
Revenue	<b>1</b> Gross receipts . . . . .	160,383			160,383
	<b>2</b> Less Contributions . . . . .	146,031			146,031
	<b>3</b> Gross income (line 1 minus line 2) . . . . .	14,352			14,352
Direct Expenses	<b>4</b> Cash prizes . . . . .				
	<b>5</b> Noncash prizes . . . . .				
	<b>6</b> Rent/facility costs . . . . .	32,334			32,334
	<b>7</b> Food and beverages . . . . .				
	<b>8</b> Entertainment . . . . .				
	<b>9</b> Other direct expenses . . . . .	8,059			8,059
	<b>10</b> Direct expense summary Add lines 4 through 9 in column (d) . . . . . ▶				40,393
<b>11</b> Net income summary Subtract line 10 from line 3, column (d) . . . . . ▶				-26,041	

**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))
		<b>1</b> Gross revenue . . . . .			
Direct Expenses	<b>2</b> Cash prizes . . . . .				
	<b>3</b> Noncash prizes . . . . .				
	<b>4</b> Rent/facility costs . . . . .				
	<b>5</b> Other direct expenses . . . . .				
	<b>6</b> 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	
<b>7</b> Direct expense summary Add lines 2 through 5 in column (d) . . . . . ▶					
<b>8</b> 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 \_\_\_\_\_

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

**b** If "Yes," explain \_\_\_\_\_

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- 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
- |          |                             |   |
|----------|-----------------------------|---|
| <b>a</b> | The organization's facility | % |
| <b>b</b> | An outside facility         | % |

**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

2018

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?
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

Table with 8 columns: (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. Row 1: 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 1

**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	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 matched the CHI grant with an additional \$44,080 of funds providing a one-year grant in the amount of \$84,080 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

**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](http://www.irs.gov/Form990) for the latest information.

OMB No 1545-0047

**2018**

**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 2 Description of Business or Family Relationship of Officers, Directors, Et	Randy and Jeffrey Hart are married

**990 Schedule O, Supplemental Information**

<b>Return Reference</b>	<b>Explanation</b>
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**

<b>Return Reference</b>	<b>Explanation</b>
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**

<b>Return Reference</b>	<b>Explanation</b>
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