

Part V Other Information (Note the Schedule A and personal benefit contract statement requirements in the instructions for Part V) Check if the organization used Schedule O to respond to any question in this Part V

33 Did the organization engage in any significant activity not previously reported to the IRS? If "Yes," provide a detailed description of each activity in Schedule O
34 Were any significant changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the amended documents if they reflect a change to the organization's name. Otherwise, explain the change on Schedule O (see instructions)
35a Did the organization have unrelated business gross income of \$1,000 or more during the year from business activities (such as those reported on lines 2, 6a, and 7a, among others)?
35b If "Yes," to line 35a, has the organization filed a Form 990-T for the year? If "No," provide an explanation in Schedule O
35c Was the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization subject to section 6033(e) notice, reporting, and proxy tax requirements during the year? If "Yes," complete Schedule C, Part III
36 Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N
37a Enter amount of political expenditures, direct or indirect, as described in the instructions
37b Did the organization file Form 1120-POL for this year?
38a Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee or were any such loans made in a prior year and still outstanding at the end of the tax year covered by this return?
38b If "Yes," complete Schedule L, Part II and enter the total amount involved
39 Section 501(c)(7) organizations. Enter:
39a Initiation fees and capital contributions included on line 9
39b Gross receipts, included on line 9, for public use of club facilities
40a Section 501(c)(3) organizations Enter amount of tax imposed on the organization during the year under: section 4911; section 4912; section 4955
40b Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year, or did it engage in an excess benefit transaction in a prior year that has not been reported on any of its prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I
40c Section 501(c)(3) and 501(c)(4) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958
40d Section 501(c)(3) and 501(c)(4) organizations Enter amount of tax on line 40c reimbursed by the organization
40e All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T
41 List the states with which a copy of this return is filed
42a The organization's books are in care of Julie Raskin Telephone no. 973-544-8372 Located at 11 Summit St Glen Ridge NJ ZIP + 4 07028
42b 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)? If "Yes," enter the name of the foreign country: See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.
42c At any time during the calendar year, did the organization maintain an office outside the U.S.? If "Yes," enter the name of the foreign country:
43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041—Check here and enter the amount of tax-exempt interest received or accrued during the tax year
44a Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ
44b Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ
44c Did the organization receive any payments for indoor tanning services during the year?
44d If "Yes" to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O
45a Did the organization have a controlled entity within the meaning of section 512(b)(13)?
45b Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," Form 990 and Schedule R may need to be completed instead of Form 990-EZ (see instructions)

		Yes	No
46 Did the organization engage, directly or indirectly, in political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	46		X

Part VI Section 501(c)(3) organizations only

All section 501(c)(3) organizations must answer questions 47-49b and 52, and complete the tables for lines 50 and 51

Check if the organization used Schedule O to respond to any question in this Part VI

		Yes	No
47 Did the organization engage in lobbying activities or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II	47		X
48 Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	48		X
49a Did the organization make any transfers to an exempt non-charitable related organization?	49a		X
b If "Yes," was the related organization a section 527 organization?	49b		
50 Complete this table for the organization's five highest compensated employees (other than officers, directors, trustees and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."			

(a) Name and title of each employee paid more than \$100,000	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
None				

f Total number of other employees paid over \$100,000 ▶ _____

51 Complete this table for the organization's five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and address of each independent contractor paid more than \$100,000	(b) Type of service	(c) Compensation
None		

d Total number of other independent contractors each receiving over \$100,000 ▶ _____

52 Did the organization complete Schedule A? **Note:** All section 501(c)(3) organizations and 4947(a)(1) nonexempt charitable trusts must attach a completed Schedule A ▶ Yes No

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: <u>Matthew Hopkins</u> Type or print name and title: <u>MATTHEW HOPKINS, PRESIDENT</u>	Date: <u>June 4, 2013</u>
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Paid Preparer Use Only	Print/Type preparer's name Thomas Conk	Preparer's signature <u>Thomas Conk</u>	Date 29 May 2013	Check <input checked="" type="checkbox"/> if self-employed	PTIN P00115308
	Firm's name ▶ Thomas E Conk CPA			Firm's EIN ▶ 22-2988393	
	Firm's address ▶ 36 Warren Pl Montclair NJ 07042			Phone no 973-744-3307	

May the IRS discuss this return with the preparer shown above? See instructions ▶ Yes No

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support

OMB No 1545-0047

2012

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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. ▶ See separate instructions.

Name of the organization Congenital Hyperinsulinism International	Employer identification number 20-3068945
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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 11, 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.)
- 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 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.)
- 10 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 11 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 that describes the type of supporting organization and complete lines 11e through 11h.
 - a Type I b Type II c Type III—Functionally integrated d Type III—Non-functionally integrated
- e By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?
 - (i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
 - (ii) A family member of a person described in (i) above?
 - (iii) A 35% controlled entity of a person described in (i) or (ii) above?

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of monetary support
			Yes	No	Yes	No	Yes	No	
(A)									
(B)									
(C)									
(D)									
(E)									
Total									0

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

Schedule A (Form 990 or 990-EZ) 2012

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
 (Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3						
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4.						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4						
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
11 Total support. Add lines 7 through 10						
12 Gross receipts from related activities, etc. (see instructions)					12	
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f))	14		%
15 Public support percentage from 2011 Schedule A, Part II, line 14	15		%
16a 33 1/3% support test—2012. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization			<input type="checkbox"/>
b 33 1/3% support test—2011. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization			<input type="checkbox"/>
17a 10%-facts-and-circumstances test—2012. 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 IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization			<input type="checkbox"/>
b 10%-facts-and-circumstances test—2011. 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 IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization			<input type="checkbox"/>
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions			<input type="checkbox"/>

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 9 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants")	18,009	17,472	37,330	24,447	53,580	150,838
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose		3,000	2,210	19,107	17,654	41,971
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5	18,009	20,472	39,540	43,554	71,234	192,809
7a Amounts included on lines 1, 2, and 3 received from disqualified persons	800	1,545	500	1,255	14,400	18,500
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b	800	1,545	500	1,255	14,400	18,500
8 Public support (Subtract line 7c from line 6)						174,309

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6	18,009	20,472	39,540	43,554	71,234	192,809
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						192,809
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ► <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f))	15	90.41 %
16 Public support percentage from 2011 Schedule A, Part III, line 15	16	96.89 %

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f))	17	0.00 %
18 Investment income percentage from 2011 Schedule A, Part III, line 17	18	0.00 %
19a 33 1/3% support tests—2012. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization ► <input checked="" type="checkbox"/>		
b 33 1/3% support tests—2011. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization ► <input type="checkbox"/>		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ► <input type="checkbox"/>		

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

OMB No 1545-0047

2012

**Open to Public
Inspection**

Name of the organization

Congenital Hyperinsulinism International

Employer identification number

20-3068945

Part I - Line 16

Insurance - \$430

Supplies - \$404

Bank Fees - \$261

Miscellaneous - \$402

Program Costs - \$13,330

Marketing - \$1,503

Total \$16,330

Part III

See attached

Part V - Line 34

Removed Section relating to Membership and Member Organizations

Removed the possibility to have Board members compensated

Board members may be elected for three terms, renewable twice, for a total
of 3 two-year terms

We elect one half of the officers every other year

Removed the "creation of a Board position" step prior to electing a new
Board member

Removed provisional Board membership

Name of the organization

Employer identification number

Congenital Hyperinsulinism International

20-3068945

Area with horizontal dashed lines for additional information.

Addendum to Schedule O

Part III

The organization works to improve the lives of babies, children, and adults affected by congenital hyperinsulinism. We provide education, information and support to these families. We also work to promote knowledge and awareness of the disorder as it leads to timely diagnosis, better care and neurological outcomes.

Line 28

Congenital Hyperinsulinism International (CHI) provides educational resources on congenital hyperinsulinism to patients, families, medical professionals, school personnel, and any other interested parties. CHI also organizes conferences and meetings for patient, patient family populations, and interested medical personnel. \$25,801. 500 people benefit from these activities.

Line 29

CHI supports research and development to better understand, treat, manage and hopefully cure congenital hyperinsulinism. CHI encourages donations to researchers and hospitals that are on the cutting edge of treatment and/or researching for a cure for the disorder. CHI is working to develop a patient registry that will include information that will foster research and knowledge of natural histories of HI patients. \$2,685. 1000 people benefit from these activities.

Line 30

CHI increases awareness of congenital hyperinsulinism in order to improve timely diagnosis, especially among medical personnel who have a direct opportunity to detect it, in order to decrease adverse neurological outcomes. We do this work by distributing our brochure to medical professionals, providing information on the CHI website about the dangers of prolonged hypoglycemia to medical professionals and other first responders, holding events for the general public, and working with endocrinologists to improve standards of care. \$9,357. 500 people benefit from these activities.

Line 31

CHI advocates on behalf of families living around the world with congenital hyperinsulinism to help them receive access to excellent medical care and services. CHI provides emotional support to families for whom the demands of the disorder take an emotional toll. (Individual support to families includes time spent working on individual cases, blog posts, and social media). \$7,320. 500 people benefit from these activities.

Officers and Directors of Congenital Hyperinsulinism International

Name	Title(s)	Address & Phone #
Matthew M. Hopkins	President, Director	5 Sierra Blanca Rd. Cedar Crest, NM 87008 505-286-3031
Patricia Cymerman	Secretary, Director	1250 South Beverly Glen Blvd. #204 Los Angeles, CA 90024 310-278-1768
Jeffrey R. Hart	Director	12 Sunnyside Lane Hillsborough, NJ 08844 908-904-9505
Randy A. Hart	Director	12 Sunnyside Lane Hillsborough, NJ 08844 908-904-9505
Davelyn Hood	Director	18207 Mantle Drive San Antonio, TX 78258 210-239-5809
Isabel Calderón	Director, Vice President	150 de l'Église C.P. 203 Clarke City, Québec Canada G0G 1H0 418-583-2604
Margaret Maher	Director	3 Kowen Pl Jerrabomberra NSW 2619 Australia 61-2-6255-8576
Mason Smith	Treasurer Director	50 Emerson Road Wellesley, MA 02481 781-235-4314
Pam Williams	Director	4 Hayes Hill Drive Northport, NY 11768 631-754-9386