

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

OMB No 1545-0047

2001

Open to Public Inspection

Department of the Treasury Internal Revenue Service

The organization may have to use a copy of this return to satisfy state reporting requirements

A For the 2001 calendar year, or tax year beginning 2001, and ending 20

- B Check if applicable: Address change, Name change, Initial return, Final return, Amended return, Application pending

C Name of organization: CHARGE SYNDROME FOUNDATION. D Employer identification number: 43-1642150. E Telephone number: (573) 499-4694. F Accounting method: Cash

Section 501(c)(3) organizations and 4947(a)(1) nonexempt charitable trusts must attach a completed Schedule A (Form 990 or 990-EZ).

- H and I are not applicable to section 527 organizations. H(a) Is this a group return for affiliates? H(b) If "Yes" enter number of affiliates. H(c) Are all affiliates included? H(d) Is this a separate return filed by an organization covered by a group ruling?

G Web site: j

J Organization type (check only one) 501(c)3 (insert no) 4947(a)(1) or 527

K Check here if the organization's gross receipts are normally not more than \$25,000. The organization need not file a return with the IRS but if the organization received a Form 990 Package in the mail it should file a return without financial data. Some states require a complete return.

L Gross receipts Add lines 6b, 8b, 9b, and 10b to line 12 j

M Check if the organization is not required to attach Sch B (Form 990, 990-EZ, or 990-PF)

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (See Specific Instructions on page 16)

Table with 21 rows and 4 columns: Description, (A) Securities, (B) Other, and Total. Includes items like Contributions, Program service revenue, Membership dues, Dividends, Gross rents, Net rental income, Other investment income, Gross amount from sales of assets, Special events, Gross sales of inventory, Other revenue, Total revenue, Program services, Management and general, Fundraising, Payments to affiliates, Total expenses, Excess or deficit, Net assets at beginning and end of year.

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Part II Statement of Functional Expenses

All organizations must complete column (A). Columns (B), (C), and (D) are required for section 501(c)(3) and (4) organizations and section 4947(a)(1) nonexempt charitable trusts but optional for others. (See Specific Instructions on page 21.)

Do not include amounts reported on line 6b, 8b, 9b, 10b, or 16 of Part I		(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
22	Grants and allocations (attach schedule) (cash \$ <u>5,000</u> noncash \$ <u>4,895</u>)	22 9,895	9895		
23	Specific assistance to individuals (attach schedule)	23			
24	Benefits paid to or for members (attach schedule)	24			
25	Compensation of officers, directors, etc	25 12,537	6000	6000	537
26	Other salaries and wages	26			
27	Pension plan contributions	27			
28	Other employee benefits	28			
29	Payroll taxes	29 933		933	
30	Professional fundraising fees	30			
31	Accounting fees	31			
32	Legal fees	32			
33	Supplies	33 1,215	1000	215	
34	Telephone	34 1,136	1000	136	
35	Postage and shipping	35 4,528	3500	800	228
36	Occupancy	36			
37	Equipment rental and maintenance	37 1,090		1,090	
38	Printing and publications	38 7,506	7000	300	206
39	Travel	39 5,565		5565	
40	Conferences, conventions, and meetings	40 74,729	74729		
41	Interest	41			
42	Depreciation, depletion, etc (attach schedule)	42			
43	Other expenses not covered above (itemize) a <u>BOARD EXP</u>	43a 3,476		3476	
b	<u>MISC</u>	43b 1,538	500	444	594
c	<u>RENTAL UNIT</u>	43c 280 1,370		1370	280
d		43d			
e		43e			
44	Total functional expenses (add lines 22 through 43) Organizations completing columns (B)-(D), carry these totals to lines 13-15	44 124,428	103,624	19,239	15,65

Joint Costs Check if you are following SOP 98-2
 Are any joint costs from a combined educational campaign and fundraising solicitation reported in (B) Program services? Yes No
 If "Yes," enter (i) the aggregate amount of these joint costs \$ _____, (ii) the amount allocated to Program services \$ _____,
 (iii) the amount allocated to Management and general \$ _____, and (iv) the amount allocated to Fundraising \$ _____

Part III Statement of Program Service Accomplishments (See Specific Instructions on page 24)

What is the organization's primary exempt purpose? <u>EDUCATE AND SUPPORT</u>	Program Service Expenses (Required for 501(c)(3) and (4) orgs and 4947(a)(1) trusts, but optional for others)
a PROVIDE INF ABOUT CHARGE SYND THROUGH PUBLICATION; PROVIDE SUPPORT TO FAMILIES W/A CHARGE MEMBER; PROVIDE BIENNIAL CONF; SUPPORT RESEARCH INTO CAUSE (Grants and allocations \$ <u>9895</u>)	103,624 124,428
b _____ (Grants and allocations \$ _____)	
c _____ (Grants and allocations \$ _____)	
d _____ (Grants and allocations \$ _____)	
e Other program services (attach schedule) (Grants and allocations \$ _____)	
f Total of Program Service Expenses (should equal line 44, column (B), Program services)	<u>103,624</u>

Part IV Balance Sheets (See Specific Instructions on page 24)

Note		(A)		(B)
Where required, attached schedules and amounts within the description column should be for end-of-year amounts only		Beginning of year		End of year
45	Cash - non-interest-bearing	43,109	45	35,826
46	Savings and temporary cash investments	71,704	46	73,091
47a	Accounts receivable			
b	Less allowance for doubtful accounts		47c	
48a	Pledges receivable			
b	Less allowance for doubtful accounts		48c	
49	Grants receivable		49	
50	Receivables from officers, directors, trustees, and key employees (attach schedule)		50	
A	51a Other notes and loans receivable (attach schedule)			
s	b Less allowance for doubtful accounts		51c	
s	52 Inventories for sale or use		52	
e	53 Prepaid expenses and deferred charges		53	
t	54 Investments - securities (attach schedule)		54	
s	55a Investments - land, buildings, and equipment basis			
	b Less accumulated depreciation (attach schedule)		55c	
	56 Investments - other (attach schedule)		56	
	57a Land, buildings, and equipment basis			
	b Less accumulated depreciation (attach schedule)		57c	
	58 Other assets (describe j _____)		58	
	59 Total assets (add lines 45 through 58) (must equal line 74)	114,813	59	108,917
L	60 Accounts payable and accrued expenses		60	
i	61 Grants payable		61	
a	62 Deferred revenue		62	
b	63 Loans from officers, directors, trustees, and key employees (attach schedule)		63	
l	64a Tax-exempt bond liabilities (attach schedule)		64a	
i	b Mortgages and other notes payable (attach schedule)		64b	
t	65 Other liabilities (describe j _____)		65	
i	66 Total liabilities (add lines 60 through 65)		66	
e	Organizations that follow SFAS 117, check here j <input checked="" type="checkbox"/> and complete lines 67 through 69 and lines 73 and 74			
s	67 Unrestricted	43,149	67	35,826
	68 Temporarily restricted	71,664	68	73,091
	69 Permanently restricted		69	
N	Organizations that do not follow SFAS 117, check here j <input type="checkbox"/> and complete lines 70 through 74			
F	70 Capital stock, trust principal, or current funds		70	
e	71 Paid-in or capital surplus, or land, building, and equipment fund		71	
u	72 Retained earnings, endowment, accumulated income, or other funds		72	
n	73 Total net assets or fund balances (add lines 67 through 69 OR lines 70 through 72, column (A) must equal line 19, column (B) must equal line 21)	114,813	73	108,917
d	74 Total liabilities and net assets / fund balances (add lines 66 and 73)	114,813	74	108,917

Form 990 is available for public inspection and, for some people, serves as the primary or sole source of information about a particular organization. How the public perceives an organization in such cases may be determined by the information presented on its return. Therefore, please make sure the return is complete and accurate and fully describes, in Part III, the organization's programs and accomplishments.

Part VI Other Information (See Specific Instructions on page 27)		Yes	No
76	Did the organization engage in any activity not previously reported to the IRS? If "Yes," attach a detailed description of each activity	76	X
77	Were any changes made in the organizing or governing documents but not reported to the IRS? If "Yes," attach a conformed copy of the changes	77	X
78a	Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?	78a	X
b	If "Yes," has it filed a tax return on Form 990-T for this year?	78b	
79	Was there a liquidation, dissolution, termination, or substantial contraction during the year? If "Yes," attach a statement	79	X
80a	Is the organization related (other than by association with a statewide or nationwide organization) through common membership, governing bodies, trustees, officers, etc., to any other exempt or nonexempt organization?	80a	X
b	If "Yes," enter the name of the organization <u>j</u> _____ and check whether it is <input type="checkbox"/> exempt OR <input type="checkbox"/> nonexempt		
81a	Enter direct or indirect political expenditures. See line 81 instructions	81a	
b	Did the organization file Form 1120-POL for this year?	81b	
82a	Did the organization receive donated services or the use of materials, equipment, or facilities at no charge or at substantially less than fair rental value?	82a	X
b	If "Yes," you may indicate the value of these items here. Do not include this amount as revenue in Part I or as an expense in Part II (See instructions in Part III)	82b	
83a	Did the organization comply with the public inspection requirements for returns and exemption applications?	83a	X
b	Did the organization comply with the disclosure requirements relating to quid pro quo contributions?	83b	X
84a	Did the organization solicit any contributions or gifts that were not tax deductible?	84a	X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	84b	
85	501(c)(4), (5), or (6) organizations a Were substantially all dues nondeductible by members?	85a	
b	Did the organization make only in-house lobbying expenditures of \$2,000 or less?	85b	
	If "Yes" was answered to either 85a or 85b, do not complete 85c through 85h below unless the organization received a waiver for proxy tax owed for the prior year		
c	Dues, assessments, and similar amounts from members	85c	
d	Section 162(e) lobbying and political expenditures	85d	
e	Aggregate nondeductible amount of section 6033(e)(1)(A) dues notices	85e	
f	Taxable amount of lobbying and political expenditures (line 85d less 85e)	85f	
g	Does the organization elect to pay the section 6033(e) tax on the amount on line 85f?	85g	
h	If section 6033(e)(1)(A) dues notices were sent, does the organization agree to add the amount on line 85f to its reasonable estimate of dues allocable to nondeductible lobbying and political expenditures for the following tax year?	85h	
86	501(c)(7) orgs Enter a Initiation fees and capital contributions included on line 12	86a	
b	Gross receipts, included on line 12, for public use of club facilities	86b	
87	501(c)(12) orgs Enter a Gross income from members or shareholders	87a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)	87b	
88	At any time during the year, did the organization own a 50% or greater interest in a taxable corporation or partnership, or an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Part IX	88	
89a	501(c)(3) organizations Enter Amount of tax imposed on the organization during the year under section 4911 <u>j</u> _____, section 4912 <u>j</u> _____, section 4955 <u>j</u> _____		
b	501(c)(3) and 501(c)(4) orgs Did the organization engage in any section 4958 excess benefit transaction during the year or did it become aware of an excess benefit transaction from a prior year? If "Yes," attach a statement explaining each transaction	89b	
c	Enter Amount of tax imposed on the organization managers or disqualified persons during the year under sections 4912, 4955, and 4958	<u>j</u> _____	
d	Enter Amount of tax on line 89c, above, reimbursed by the organization	<u>j</u> _____	
90a	List the states with which a copy of this return is filed <u>j</u> _____		
b	Number of employees employed in the pay period that includes March 12, 2001 (See instructions)	90b	
91	The books are in care of <u>j</u> MARION NORBURY Telephone no <u>j</u> 573-499-4696 Located at <u>j</u> 2004 PARKADE COLUMBIA MO ZIP + 4 <u>j</u> 65202-312		
92	Section 4947(a)(1) nonexempt charitable trusts filing Form 990 in lieu of Form 1041 - Check here <input type="checkbox"/> and enter the amount of tax-exempt interest received or accrued during the tax year <u>j</u> 92		

Part VII Analysis of Income-Producing Activities		(See Specific Instructions on page 32)				
Note Enter gross amounts unless otherwise indicated		Unrelated business income		Excluded by section 512, 513 or 514		(E) Related or exempt function income
		(A) Business code	(B) Amount	(C) Exclusion code	(D) Amount	
93	Program service revenue					
a	VARIOUS		39,495			
b						
c						
d						
e						
f	Medicare/Medicaid payments					
g	Fees and contracts from government agencies					
94	Membership dues and assessments					
95	Interest on savings and temporary cash investments					
96	Dividends and interest from securities					
97	Net rental income or (loss) from real estate					
a	debt-financed property					
b	not debt-financed property					
98	Net rental income or (loss) from personal property					
99	Other investment income					
100	Gain or (loss) from sales of assets other than inventory					
101	Net income or (loss) from special events					
102	Gross profit or (loss) from sales of inventory					
103	Other revenue a					
b						
c						
d						
e						
104	Subtotal (add columns (B), (D), and (E))		39,495			
105	Total (add line 104, columns (B), (D), and (E))					39,495

Note Line 105 plus line 1d, Part I, should equal the amount on line 12, Part I

Part VIII Relationship of Activities to the Accomplishment of Exempt Purposes (See Specific Instructions on page 32)

Line No	Explain how each activity for which income is reported in column (E) of Part VII contributed importantly to the accomplishment of the organization's exempt purposes (other than by providing funds for such purposes)
▼	

Part IX Information Regarding Taxable Subsidiaries and Disregarded Entities (See Specific Instructions on page 33)

(A) Name, address, and EIN of corporation, partnership, or disregarded entity	(B) Percentage of ownership interest	(C) Nature of activities	(D) Total income	(E) End-of-year assets
	%			
	%			
	%			
	%			

Part X Information Regarding Transfers Associated with Personal Benefit Contracts (See Specific Instructions on page 33)

- (a) Did the organization during the year receive any funds, directly or indirectly to pay premiums on a personal benefit contract? Yes No
- (b) Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? Yes No

Note If "Yes" to (b), file Form 8870 and Form 4720 (see instructions)

Please [Signature]
 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
 Date 6-15-02
 Executive Director

Date _____ Check # _____ Preparer's SSN or PTIN (See Gen. Inst. W)

SCHEDULE A
(Form 990 or 990-EZ)

Organization Exempt Under Section 501(c)(3)

(Except Private Foundation) and Section 501(e), 501(f), 501(k),
501(n), or Section 4947(a)(1) Nonexempt Charitable Trust

Supplementary Information -- (See separate instructions.)

OMB No 1545-0047

2001

Department of the Treasury
Internal Revenue Service

j MUST be completed by the above organizations and attached to their Form 990 or 990-EZ

Name of the organization

Employer identification number

CHARGE SYNDROME FOUNDATION

43-1642150

Part I Compensation of the Five Highest Paid Employees Other Than Officers, Directors, and Trustees

(See page 1 of the instructions List each one If there are none, enter "None")

(a) Name and address of each employee paid more than \$50,000	(b) Title and average hours per week devoted to position	(c) Compensation	(d) Contributions to employee benefit plans & deferred compensation	(e) Expense account and other allowances
None				

Total number of other employees paid over \$50,000 **j**

Part II Compensation of the Five Highest Paid Independent Contractors for Professional Services

(See page 2 of the instructions List each one (whether individuals or firms) If there are none, enter "None")

(a) Name and address of each independent contractor paid more than \$50,000	(b) Type of service	(c) Compensation
None		

Total number of others receiving over \$50,000 for professional services **j**

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

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

Supplementary Information for
line 1 of Form 990, 990-EZ and 990-PF (see instructions)

OMB No 1545-0047

2001

Name of organization

Employer identification number

CHARGE SYNDROME FOUNDATION

43-1642150

Organization type (check one)

Filers of

Section

Form 990 or 990-EZ

501(c) (3) (enter number) organization

4947(a)(1) nonexempt charitable trust not treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

Check if your organization is covered by the General rule or a Special rule (Note. Only a section 501(c)(7), (8), or (10) organization can check box(es) for both the General rule and a Special rule - see instructions)

General Rule -

For organizations filing Form 990, 990-EZ, or 990-PF that received, during the year, \$5,000 or more (in money or property) from any one contributor (Complete Parts I and II)

Special Rules -

For a section 501(c)(3) organization filing Form 990, or Form 990-EZ, that met the 33 1/3% support test of the regulations under sections 509(a)(1)/170(b)(1)(A)(vi) and received from any one contributor, during the year, a contribution of the greater of \$5,000 or 2% of the amount on line 1 of these forms (Complete Parts I and II)

For a section 501(c)(7), (8), or (10) organization filing Form 990, or Form 990-EZ, that received from any one contributor, during the year, aggregate contributions or bequests of more than \$1,000 for use exclusively for religious, charitable, scientific, literary, or educational purposes, or the prevention of cruelty to children or animals (Complete Parts I, II, and III)

For a section 501(c)(7), (8), or (10) organization filing Form 990, or Form 990-EZ, that received from any one contributor, during the year, some contributions for use exclusively for religious, charitable, etc , purposes, but these contributors did not aggregate to more than \$1,000 (If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc , purpose Do not complete any of the Parts unless the General rule applies to this organization because it received nonexclusively religious, charitable etc , contributions of \$5,000 or more during the year)

j \$ _____

Caution Organizations that are not covered by the General rule and/or the Special rules do not file Schedule B (Form 990, 990-EZ, or 990-PF) but they must check the box in the heading of their Form 990, Form 990 EZ, or on line 1 of their Form 990-PF, to certify that they do not meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF)

Name of organization: **CHARGE SYNDROME FOUNDATION** Employer Identification number: **43-1642150**

Part I Contributors (See Specific Instructions)

(a) No.	(b) Name, address and ZIP + 4	(c) Aggregate contributions	(d) Type of contribution
1		\$ 11,500	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution)
2		\$ 5,000	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution)
—	\$	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution)
—	\$	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution)
—	\$	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution)
—	\$	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution)

LINE 22

2001
STM 01
PG01

Name(s) shown on return

CHARGE SYNDROME FOUNDATION

Identifying Number

43-1642150

CASH 5000 WAS GIVENE TO IWK HEALTH CENTER FOR RESEARCH
NONCASH 4895 WAS PAYING FOR FAMILIES TO ATTEND THE
CHARGE CONFERENCE

Form 990 - Part V

List of Officers, Directors, Trustees, and Key Employees

Name(s) shown on return		Identifying Number		
CHARGE SYNDROME FOUNDATION		43-1642150		
(A)	Title and	(C)	(D)	(E)
Name and address	Average Hrs	Compensation	Contrib.	Expense
BRUCE APPELL 2004 PARKADE COLUMBIA MO	PRESIDENT 5		0	
NEAL STANGER 2004 PARKDADE COLUMBIA MO	VICE PRES 5		0	
RICK OGAN 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
COLLEEN FEATHEN 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
PHYLLIS FISHER 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
PETER GARAFALO 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
NANCY HARTSHOREN 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
MEG HEFNER 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
DONNA LACEY 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
BROWNIE SHOTT 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
WENDI WOOD 2004 PARKADE COLUMBIA MO	SEC/TREAS 2		0	
DENNIS OTOOLE 2004 PARKADE COLUMBIA MO	DIRECTOR		0	
MARION NORBURY 2004 PARKADE COLUMBIA MO	EXECUTIVE DIR 20	12,500		

CHARGE Syndrome Foundation, Inc.

BYLAWS

ARTICLE I NAME

The name of this Foundation shall be The CHARGE Syndrome Foundation, Inc. [Hereinafter the "Foundation"]

ARTICLE II LOCATION

The principal location of this Foundation shall be in the State of Missouri.

ARTICLE III PURPOSE

Section 1. This Foundation is organized exclusively for charitable, educational, religious, or scientific purposes within the meaning of Section 501 (c)(3) of the Internal Revenue Code.

Section 2 The purpose of this Foundation shall be:

- A. to establish, maintain, and distribute information about CHARGE Syndrome to any and all interested persons;
- B. to provide support to families with a CHARGE member;
- C. to further the development of information about CHARGE Syndrome, its causes and effect on the person so afflicted, their family and others who work with them,
- D. to support research into the cause and treatment of CHARGE Syndrome;
- E. to solicit and receive gifts from individuals and organizations,
- F. to do all things alone or in conjunction with other persons, organizations, or institutions proper or desirable for accomplishing the purposes of the Foundation; and
- G. to do and exercise any and all general powers, whether herein enumerated or not, which a non-profit corporation may or can exercise under the laws and Constitution of the State of Missouri

ARTICLE IV MEMBERSHIP

Section 1. Membership is open to anyone who supports the purposes of the CHARGE Syndrome Foundation.

- A. Individuals, families and friends
- B. Professionals
- C. Organizations, institutions, libraries

ARTICLE V DUES

Section 1. Annual dues are payable on or before January 1 of each year.

Section 2 Dues for members shall be determined by the Board of Directors.

Section 3. For new members, their year will begin on January 1 of the current year They will receive all of that year's issues of the Foundation's newsletter, **CHARGE Accounts**

Section 4. Dues will be waived for families who cannot afford the fee upon written request for the waiver.

Section 5 A subscription to **CHARGE Accounts** is included in a member's dues.

ARTICLE VI MEETINGS

Section 1. **BIENNIAL MEETING.** The biennial membership meeting shall be held in conjunction with the Foundation's conference

ARTICLE VII BOARD OF DIRECTORS

Section 1. **COMPOSITION.** The Board of Directors shall be composed of twelve (12) voting members of which at least 7 shall be individuals with CHARGE or their family members. Only one (1) person from a family may serve on the board of directors at any one time. (2001 Conference)

Section 2 ELECTION

- A. Directors will serve four year terms with election on an overlapping basis.
- B. Directors will be elected by mail prior to the biennial conference. The six (6) persons receiving the highest number of votes will be elected. (2001 Conference)
- C. Each membership is allowed one (1) vote. (2001 Conference)
- D. Annual dues must be paid prior to election to board. (2001 Conference)

Section 3. **BIENNIAL MEETING.** The biennial meeting shall be held by the Board of Directors in conjunction with the Foundation's biennial conference.

Section 4. **SPECIAL MEETINGS** Special meetings of the Board of Directors may be called at any time by the President or by one-third of the Board members. Written notice of any special meeting shall be given to each member not less than five (5) days before the meeting. The notice shall state the date, time, place and purpose for which the meeting is called. Such meetings may be conducted by electronic means (i.e. conference call, internet).

Section 5. DUTIES. The Board of Directors

- A. shall determine the program of the Foundation
- B. shall provide consultation with experts in the field
- C. shall approve appointments of the President
- D. shall arrange for an annual audit

Section 6. **QUORUM.** A majority of all members of the Board of Directors shall constitute a quorum for the transaction of business at a regular or special meeting

Section 7. **VOTING.** Each member of this Board of Directors shall have one (1) vote at all meetings. The act of a majority of the members present shall be the act of this Board of Directors, unless the act of a greater number is required by law or by another provision herein.

Section 8. **REMOVAL FROM OFFICE.** Any board member can be voted off the board for misconduct by a two-third (2/3) vote in favor of removing said member. (2001 Conference)

Section 9. **VACANCIES.** If the position of any member of the Board of Directors becomes vacant, the vacancy shall be filled by action of the Board of Directors.

Section 10. **RESIGNATION.** Any member of the Board of Directors may resign at any time by giving written notice of such resignation to the Secretary of the Foundation.

Section 11. **COMPENSATION.** Members of the Board of Directors of the Foundation shall serve without compensation but may be reimbursed for travel expenses. The Board of Directors shall have power in its discretion to approve and pay allowable expenses incurred by a member of the Board of Directors.

ARTICLE VIII EXECUTIVE COMMITTEE

Section 1. **OFFICERS.** The officers of the Foundation shall be a President, a Vice-President, and a Secretary-Treasurer and shall constitute the Executive Committee

Section 2. DUTIES OF OFFICERS

A. President. The President shall:

1. preside at all the meetings of the Board of Directors;
2. have and exercise general charge and supervision of the affairs of the Foundation;
3. shall appoint a nominating committee of at least three (3) members six (6) or more months prior to the biennial conference,
4. will appoint other committees as deemed necessary,
5. perform all duties pertaining to the office; and
6. present an annual report of the Foundation activities in CHARGE Accounts, the Foundation's official newsletter.

B VICE-PRESIDENT The Vice-President shall perform such duties as are assigned by the president, and shall, in the absence of the President perform the required duties. In the event of a vacancy in the office of President, the Vice-President shall succeed to the office of President.

C. SECRETARY-TREASURER.

1. The Secretary shall
 - a. keep the minutes of the meetings of the Board of Directors,
 - b. maintain a current list of names and addresses of the Directors,
 - c. record attendance at board meetings;
 - d. maintain a file of essential records;
 - e. conduct the general correspondence of the Board, and
 - f. shall notify the directors of all regular and special meetings.
2. The Treasurer shall
 - a. be responsible for all funds of the Foundation;
 - b. make reports at all regular meetings of the Board of Directors.

Section 3. ELECTION. The officers shall be elected by a majority vote of the Board of Directors at the biennial meeting of the Foundation with term of office to begin at the close of the meeting at which they are elected. Officers shall serve for a term of two (2) years. A term shall be defined as more than six (6) months.

Section 4 The Officers shall have authority to act for the Board of Directors between meetings of the Board and shall report thereon to the rest of the board within thirty(30) days.

Section 5. Meetings of the Executive Committee may be conducted by electronic means (i.e. conference call, internet).

Section 6. VACANCIES. A vacancy in any office except that of President shall be filled by a majority vote of the Board of Directors at any regular or special meeting for the remainder of the unexpired term.

ARTICLE IX FOUNDATION DIRECTOR

The members of the Board of Directors may select and/or employ a qualified and competent Foundation Director who shall be the direct representative of the Foundation in carrying out its functions. It shall be the responsibility of the members of the Board of Directors to determine the duties and responsibilities of the Foundation Director. The Foundation Director shall serve as an ex-officio member of the Board of Directors, without vote.

ARTICLE X FISCAL YEAR

The fiscal year of the Foundation shall be from January 1 through December 31.

ARTICLE XI INUREMENT OF INCOME

No part of the net earnings of the Foundation shall inure to the benefit of, or be distributable to, its members, directors, officers or other private persons except that the Foundation shall be authorized and empowered to pay reasonable compensation for services rendered.

ARTICLE XII LEGISLATIVE OR POLITICAL ACTIVITIES

No substantial part of the activities of the Foundation shall be the carrying on of propaganda or otherwise attempting to influence legislation and the Foundation shall not participate in or intervene (including the publishing or distribution of statements) in any political campaign on behalf of any candidate for public office.

ARTICLE XIII OPERATIONAL LIMITATIONS

Notwithstanding any other provisions of these articles, the Foundation shall not carry on any other activities not permitted to be carried on (a) by a foundation exempt from Federal Income Tax under Section 501 (c)(3) of the Internal Revenue Code of 1954 (or the corresponding provision of any future United States Internal Revenue Law) or (b) by a foundation, contributions to which are deductible under Section 170 (c)(2) of the Internal Revenue Code of 1954 (or the corresponding provision of any future United States Internal Revenue Law).

ARTICLE XIV DISSOLUTION

Upon the dissolution of the Foundation, the Board of Directors shall, after paying or making provisions for the payment of all of the liabilities of the Foundation, dispose of all the assets of the Foundation exclusively for the purposes of the Foundation in such manner, or to such organization or organizations organized and operated exclusively for charitable, educational, religious, or scientific purposes as shall at the time qualify as an exempt organization or organizations under Section 501 (c)(3) of the Internal Revenue Code of 1954 (or the corresponding provision of any future United States Internal Revenue Law), as the Board of Directors shall determine.

Any such assets not so disposed of shall be disposed of by the Circuit Court of the county in which the principal office of the Foundation is then located, exclusively for such purposes or to such organization or organizations, as said Court shall determine, which are organized and operated exclusively for such purposes.

ARTICLE XV PARLIAMENTARY AUTHORITY

The rules contained in the current edition of Roberts Rules of Order Newly Revised shall govern the Foundation in all cases to which they are applicable and in which they are not inconsistent with these bylaws and any special rules of order the Foundation may adopt.

ARTICLE XVI AMENDMENT OF BYLAWS

Section 1. The Board of Directors shall recommend to the membership any bylaws changes prior to the biennial meeting. Final approval to amend or rescind these bylaws requires a 2/3 vote of those members present and voting.

Section 2. The Secretary shall send notice of proposed changes or amendments to these bylaws to each member of the Foundation at least thirty (30) days prior to meeting at which they are to be voted.

Revised March 27, 1997
Revised July 21, 2001

Marian A. Noshay
Exec. Dir.

These Proposed Amendments were passed at the 5th International CHARGE Syndrome Conference on July 22, 2001.

ARTICLE VII BOARD OF DIRECTORS

Section 1 COMPOSITION The Board of Directors shall be composed of twelve (12) voting members of which at least 7 shall be individuals with CHARGE or their family members

ADD Only one (1) person from a family may serve on the board of directors at any one time.

Section 2 ELECTION

A Directors will serve four year terms with election on an overlapping basis

B Directors will be elected by mail prior to the biennial conference

ADD to B. The six (6) persons receiving the highest number of votes will be elected.

ADD NEW "C" and "D"

C. Each membership is allowed one (1) vote.

D. Annual dues must be paid prior to election to board.

Section 3 BIENNIAL MEETING The biennial meeting shall be held by the Board of Directors in conjunction with the Foundation's biennial conference.

Section 4 SPECIAL MEETINGS. Special meetings of the Board of Directors may be called at any time by the President or by one-third of the Board members Written notice of any special meeting shall be given to each member not less than five (5) days before the meeting. The notice shall state the date, time, place and purpose for which the meeting is called Such meetings may be conducted by electronic means (i e conference call, internet)

Section 5 DUTIES. The Board of Directors

A shall determine the program of the Foundation

B shall provide consultation with experts in the field

C shall approve appointments of the President

D shall arrange for an annual audit

Section 6 QUORUM. A majority of all members of the Board of Directors shall constitute a quorum for the transaction of business at a regular or special meeting

Section 7 VOTING. Each member of this Board of Directors shall have one (1) vote at all meetings The act of a majority of the members present shall be the act of this Board of Directors, unless the act of a greater number is required by law or by another provision herein

New Section 8

Section 8. REMOVAL FROM OFFICE. Any board member can be voted off the board for misconduct by a two-third (2/3) vote in favor of removing said member.

Renumber Sections 8 thru 10

Section 9 VACANCIES If the position of any member of the Board of Directors becomes vacant, the vacancy shall be filled by action of the Board of Directors

Section 10 RESIGNATION. Any member of the Board of Directors may resign at any time by giving written notice of such resignation to the Secretary of the Foundation

Section 11 COMPENSATION Members of the Board of Directors of the Foundation shall serve without compensation but may be reimbursed for travel expenses The Board of Directors shall have power in its discretion to approve and pay allowable expenses incurred by a member of the Board of Directors

Application for Extension of Time to File an Exempt Organization Return

Department of the Treasury Internal Revenue Service

File a separate application for each return

If you are filing for an Automatic 3-Month Extension, complete only Part I and check this box
If you are filing for an Additional (not automatic) 3-Month Extension, complete only Part II (on page 2 of this form)

Note Do not complete Part II unless you have already been granted an automatic 3-month extension on a previously filed

Form 8868

Part I Automatic 3-Month Extension of Time - Only submit original (no copies needed)

Note Form 990-T corporations requesting an automatic 6-month extension - check this box and complete Part I only

All other corporations (including Form 990-C filers) must use Form 7004 to request an extension of time to file income tax returns Partnerships, REMICs and trusts must use Form 8736 to request an extension of time to file Form 1065 1066, or 1041

Table with 3 columns: Type or print, Name of Exempt Organization, Employer identification number. Row 1: CHARGE SYNDROME FOUNDATION, 43-1642150. Row 2: 2004 PARKADE BLVD. Row 3: COLUMBIA, MO 65202.

Check type of return to be filed (file a separate application for each return)

- Form 990, Form 990-T (corporation), Form 4720, Form 990-BL, Form 990-T (sec 401(a) or 408(a) trust), Form 5227, Form 990-EZ, Form 990 T (trust other than above), Form 6069, Form 990-PF, Form 1041-A, Form 8870.

If the organization does not have an office or place of business in the United States, check this box
If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN)
for the whole group, check this box If it is for part of the group, check this box and attach a list with the names and EINs of all members the extension will cover

1 I request an automatic 3-month (6-month, for 990-T corporation) extension of time until 20 to file the exempt organization return for the organization named above The extension is for the organization's return for calendar year 20 01 or tax year beginning 20 and ending 20

2 If this tax year is for less than 12 months, check reason Initial return Final return Change in accounting period

3a If this application is for Form 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax less any nonrefundable credits See instructions \$
b If this application is for Form 990 PF or 990-T, enter any refundable credits and estimated tax payments made Include any prior year overpayment allowed as a credit \$
c Balance Due Subtract line 3b from line 3a Include your payment with this form or, if required, deposit with FTD coupon or, if required, by using EFTPS (Electronic Federal Tax Payment System) See instructions \$

Signature and Verification

Under penalties of perjury I declare that I have examined this form, including accompanying schedules and statements and to the best of my knowledge and belief it is true correct and complete and that I am authorized to prepare this form

Signature [Handwritten Signature] Title [Handwritten Title] Date [Handwritten Date]
For Paperwork Reduction Act Notice, see instruction EEA Form 8868 (12-2000)