

Short Form

OMB No 1545-1150

Form 990-EZ

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)
For organizations with gross receipts less than \$100,000 and total assets less than \$250,000 at the end of the year
The organization may have to use a copy of this return to satisfy state reporting requirements

2005

Open to Public Inspection

Department of the Treasury Internal Revenue Service

A For the 2005 calendar year, or tax year beginning January 1, 2005, and ending December 31, 2005

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

C Name of organization
22213 Deletion Syndrome Foundation
Number and street (or P O box, if mail is not delivered to street address) Room/suite
2 Doctors Dr.
City or town, state or country, and ZIP + 4
Greenville, SC 29605

D Employer identification number
04 : 3673104
E Telephone number
(864) 250-7944
F Group Exemption Number

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

G Accounting method: Cash Accrual Other (specify)

I Website: www.22q13.com

H Check if the organization is not required to attach Schedule B (Form 990, 990-EZ, or 990-PF).

J Organization type (check only one) 501(c)(3) 4947(a)(1) or 527

K Check 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 chooses to file a return, be sure to file a complete return. Some states require a complete return.

L Add lines 5b, 6b, and 7b, to line 9 to determine gross receipts, if \$100,000 or more, file Form 990 instead of Form 990-EZ. \$ 16,416.00

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (See page 38 of the instructions.)

Table with 21 rows for Revenue, Expenses, and Net Assets. Revenue total: 16,416.00. Expenses total: 24,277.00. Net Assets total: 21,971.00.

Part II Balance Sheets—If Total assets on line 25, column (B) are \$250,000 or more, file Form 990 instead of Form 990-EZ.

Table with 7 rows for Balance Sheets. Total assets: 21,971. Total liabilities: 0. Net assets: 21,971.

P 19

Part III Statement of Program Service Accomplishments (See page 42 of the instructions.)	Expenses (Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts; optional for others)
What is the organization's primary exempt purpose? _____ Describe what was achieved in carrying out the organization's exempt purposes. In a clear and concise manner, describe the services provided, the number of persons benefited, or other relevant information for each program title.	
28 See Statement 1 _____ _____	
(Grants \$ _____) If this amount includes foreign grants, check here <input type="checkbox"/> 28a	0
29 _____ _____	
(Grants \$ _____) If this amount includes foreign grants, check here <input type="checkbox"/> 29a	
30 _____ _____	
(Grants \$ _____) If this amount includes foreign grants, check here <input type="checkbox"/> 30a	
31 Other program services (attach schedule) _____ (Grants \$ _____) If this amount includes foreign grants, check here <input type="checkbox"/> 31a	
32 Total program service expenses (add lines 28a through 31a) _____ 32	0

Part IV List of Officers, Directors, Trustees, and Key Employees (List each one even if not compensated. See page 42 of the instructions)				
(A) Name and address	(B) Title and average hours per week devoted to position	(C) Compensation (If not paid, enter -0-.)	(D) Contributions to employee benefit plans & deferred compensation	(E) Expense account and other allowances
See Statement 2 _____				

Part V Other Information (Note the attachment requirement in General Instruction V, page 14.)			Yes	No
33 Did the organization engage in any activity not previously reported to the IRS? If "Yes," attach a detailed description of each activity	33			✓
34 Were any changes made to the organizing or governing documents but not reported to the IRS? If "Yes," attach a conformed copy of the changes	34			✓
35 If the organization had income from business activities, such as those reported on lines 2, 6, and 7 (among others), but not reported on Form 990-T, attach a statement explaining your reason for not reporting the income on Form 990-T.				
a Did the organization have unrelated business gross income of \$1,000 or more or 6033(e) notice, reporting, and proxy tax requirements?	35a			✓
b If "Yes," has it filed a tax return on Form 990-T for this year?	35b			
36 Was there a liquidation, dissolution, termination, or substantial contraction during the year? (If "Yes," attach a statement)	36			✓
37a Enter amount of political expenditures, direct or indirect, as described in the instructions. 37a 0				
b Did the organization file Form 1120-POL for this year?	37b			✓
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 unpaid at the start of the period covered by this return?	38a			✓
b If "Yes," attach the schedule specified in the line 38 instructions and enter the amount involved	38b	0		
39 501(c)(7) organizations Enter:				
a Initiation fees and capital contributions included on line 9	39a			
b Gross receipts, included on line 9, for public use of club facilities	39b			
40a 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 0 ; section 4912 0 ; section 4955 0				
b 501(c)(3) and (4) organizations. 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 an explanation.	40b			✓
c Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958				0
d Enter amount of tax on line 40c reimbursed by the organization				0

Part V Other Information (Note the attachment requirement in General Instruction V, page 14.) (Continued)

41 List the states with which a copy of this return is filed. None South Carolina

42a The books are in care of Gail Stapleton Telephone no. 864-250-7944
Located at 2 Doctors Drive, Greenville, SC ZIP + 4 29605

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)?

	Yes	No
42b		<input checked="" type="checkbox"/>
42c		<input checked="" type="checkbox"/>

If "Yes," enter the name of the foreign country: _____

See the instructions for exceptions and filing requirements for Form TD F 90-22.1.

c At any time during the calendar year, did the organization maintain an office outside of 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 43

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

Please Sign Here

Gail Stapleton Date 1/30/07
Signature of officer

Gail Stapleton, Treasurer
Type or print name and title

Paid Preparer's Use Only

Preparer's signature _____ Date _____ Check if self-employed Preparer's SSN or PTIN (See Gen Inst W) _____
Firm's name (or yours if self-employed), address, and ZIP + 4 _____ EIN _____
Phone no. _____

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 4947(a)(1) Nonexempt Charitable Trust

OMB No 1545-0047

2005

Department of the Treasury
Internal Revenue Service

Supplementary Information—(See separate instructions.)

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

Name of the organization 22Q13 DELETION SYNDROME FOUNDATION	Employer identification number 04 : 3673104
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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 ▶		0		

Part II-A 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 ▶		0

Part II-B Compensation of the Five Highest Paid Independent Contractors for Other Services
(List each contractor who performed services other than professional services, whether individuals or firms. If there are none, enter "None." See page 2 of the instructions.)

(a) Name and address of each independent contractor paid more than \$50,000	(b) Type of service	(c) Compensation
None		
Total number of other contractors receiving over \$50,000 for other services ▶		0

Part III Statements About Activities (See page 2 of the instructions.)

		Yes	No
1	During the year, has the organization attempted to influence national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum? If "Yes," enter the total expenses paid or incurred in connection with the lobbying activities ► \$ _____ (Must equal amounts on line 38, Part VI-A, or line i of Part VI-B)		✓
	Organizations that made an election under section 501(h) by filing Form 5768 must complete Part VI-A. Other organizations checking "Yes" must complete Part VI-B AND attach a statement giving a detailed description of the lobbying activities.		
2	During the year, has the organization, either directly or indirectly, engaged in any of the following acts with any substantial contributors, trustees, directors, officers, creators, key employees, or members of their families, or with any taxable organization with which any such person is affiliated as an officer, director, trustee, majority owner, or principal beneficiary? (If the answer to any question is "Yes," attach a detailed statement explaining the transactions.)		
a	Sale, exchange, or leasing of property?		✓
b	Lending of money or other extension of credit?		✓
c	Furnishing of goods, services, or facilities?		✓
d	Payment of compensation (or payment or reimbursement of expenses if more than \$1,000)?		✓
e	Transfer of any part of its income or assets?		✓
3a	Do you make grants for scholarships, fellowships, student loans, etc.? (If "Yes," attach an explanation of how you determine that recipients qualify to receive payments.)		✓
b	Do you have a section 403(b) annuity plan for your employees?		✓
c	During the year, did the organization receive a contribution of qualified real property interest under section 170(h)?		✓
4a	Did you maintain any separate account for participating donors where donors have the right to provide advice on the use or distribution of funds?		✓
b	Do you provide credit counseling, debt management, credit repair, or debt negotiation services?		✓

Part IV Reason for Non-Private Foundation Status (See pages 3 through 6 of the instructions.)

The organization is not a private foundation because it is (Please check only **ONE** applicable box.)

- 5** A church, convention of churches, or association of churches. Section 170(b)(1)(A)(i).
- 6** A school. Section 170(b)(1)(A)(ii). (Also complete Part V.)
- 7** A hospital or a cooperative hospital service organization. Section 170(b)(1)(A)(iii).
- 8** A Federal, state, or local government or governmental unit. Section 170(b)(1)(A)(v).
- 9** A medical research organization operated in conjunction with a hospital. Section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state ►
- 10** An organization operated for the benefit of a college or university owned or operated by a governmental unit. Section 170(b)(1)(A)(iv). (Also complete the **Support Schedule** in Part IV-A.)
- 11a** An organization that normally receives a substantial part of its support from a governmental unit or from the general public. Section 170(b)(1)(A)(vi). (Also complete the **Support Schedule** in Part IV-A.)
- 11b** A community trust. Section 170(b)(1)(A)(vi). (Also complete the **Support Schedule** in Part IV-A.)
- 12** 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 charitable, etc., 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). (Also complete the **Support Schedule** in Part IV-A.)
- 13** An organization that is not controlled by any disqualified persons (other than foundation managers) and supports organizations described in **(1)** lines 5 through 12 above; or **(2)** sections 501(c)(4), (5), or (6), if they meet the test of section 509(a)(2). Check the box that describes the type of supporting organization: ► Type 1 Type 2 Type 3

Provide the following information about the supported organizations (See page 6 of the instructions.)

(a) Name(s) of supported organization(s)	(b) Line number from above

- 14** An organization organized and operated to test for public safety. Section 509(a)(4). (See page 6 of the instructions.)

Part IV-A Support Schedule (Complete only if you checked a box on line 10, 11, or 12.) *Use cash method of accounting.*

Note: You may use the worksheet in the instructions for converting from the accrual to the cash method of accounting.

Calendar year (or fiscal year beginning in) ▶	(a) 2004	(b) 2003	(c) 2002	(d) 2001	(e) Total
15 Gifts, grants, and contributions received. (Do not include unusual grants. See line 28).	11,068	4,448	0	0	15,516
16 Membership fees received	0	0	0	0	0
17 Gross receipts from admissions, merchandise sold or services performed, or furnishing of facilities in any activity that is related to the organization's charitable, etc., purpose	0	0	0	0	0
18 Gross income from interest, dividends, amounts received from payments on securities loans (section 512(a)(5)), rents, royalties, and unrelated business taxable income (less section 511 taxes) from businesses acquired by the organization after June 30, 1975	0	0	0	0	0
19 Net income from unrelated business activities not included in line 18.	0	0	0	0	0
20 Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf	0	0	0	0	0
21 The value of services or facilities furnished to the organization by a governmental unit without charge. Do not include the value of services or facilities generally furnished to the public without charge.	0	0	0	0	0
22 Other income. Attach a schedule. Do not include gain or (loss) from sale of capital assets	0	0	0	0	0
23 Total of lines 15 through 22	11,068	4,448	0	0	15,516
24 Line 23 minus line 17	11,068	4,448	0	0	15,516
25 Enter 1% of line 23	111	44	0	0	

26 Organizations described on lines 10 or 11: a Enter 2% of amount in column (e), line 24 ▶	26a	
b Prepare a list for your records to show the name of and amount contributed by each person (other than a governmental unit or publicly supported organization) whose total gifts for 2001 through 2004 exceeded the amount shown in line 26a. Do not file this list with your return. Enter the total of all these excess amounts ▶	26b	
c Total support for section 509(a)(1) test: Enter line 24, column (e) ▶	26c	
d Add Amounts from column (e) for lines: 18 _____ 19 _____ 22 _____ 26b _____ ▶	26d	
e Public support (line 26c minus line 26d total) ▶	26e	
f Public support percentage (line 26e (numerator) divided by line 26c (denominator)) ▶	26f	%

27 Organizations described on line 12: a For amounts included in lines 15, 16, and 17 that were received from a "disqualified person," prepare a list for your records to show the name of, and total amounts received in each year from, each "disqualified person" Do not file this list with your return. Enter the sum of such amounts for each year:

(2004) 0 (2003) 0 (2002) 0 (2001) 0

b For any amount included in line 17 that was received from each person (other than "disqualified persons"), prepare a list for your records to show the name of, and amount received for each year, that was more than the larger of (1) the amount on line 25 for the year or (2) \$5,000 (Include in the list organizations described in lines 5 through 11b, as well as individuals.) Do not file this list with your return. After computing the difference between the amount received and the larger amount described in (1) or (2), enter the sum of these differences (the excess amounts) for each year:

(2004) 0 (2003) 0 (2002) 0 (2001) 0

c Add. Amounts from column (e) for lines: 15 _____ 16 _____ 17 _____ 20 _____ 21 _____ ▶	27c	15,516
d Add Line 27a total, _____ and line 27b total ▶	27d	0
e Public support (line 27c total minus line 27d total). ▶	27e	15,516
f Total support for section 509(a)(2) test: Enter amount from line 23, column (e) ▶	27f	15,516
g Public support percentage (line 27e (numerator) divided by line 27f (denominator)) ▶	27g	100 %
h Investment income percentage (line 18, column (e) (numerator) divided by line 27f (denominator)). ▶	27h	0 %

28 Unusual Grants: For an organization described in line 10, 11, or 12 that received any unusual grants during 2001 through 2004, prepare a list for your records to show, for each year, the name of the contributor, the date and amount of the grant, and a brief description of the nature of the grant. Do not file this list with your return. Do not include these grants in line 15.

Part V Private School Questionnaire (See page 7 of the instructions.)
(To be completed ONLY by schools that checked the box on line 6 in Part IV)

		Yes	No
29	Does the organization have a racially nondiscriminatory policy toward students by statement in its charter, bylaws, other governing instrument, or in a resolution of its governing body?		
30	Does the organization include a statement of its racially nondiscriminatory policy toward students in all its brochures, catalogues, and other written communications with the public dealing with student admissions, programs, and scholarships?		
31	Has the organization publicized its racially nondiscriminatory policy through newspaper or broadcast media during the period of solicitation for students, or during the registration period if it has no solicitation program, in a way that makes the policy known to all parts of the general community it serves? If "Yes," please describe; if "No," please explain. (If you need more space, attach a separate statement.)		
32	Does the organization maintain the following:		
a	Records indicating the racial composition of the student body, faculty, and administrative staff?		
b	Records documenting that scholarships and other financial assistance are awarded on a racially nondiscriminatory basis?		
c	Copies of all catalogues, brochures, announcements, and other written communications to the public dealing with student admissions, programs, and scholarships?		
d	Copies of all material used by the organization or on its behalf to solicit contributions?		
	If you answered "No" to any of the above, please explain (If you need more space, attach a separate statement.)		
33	Does the organization discriminate by race in any way with respect to:		
a	Students' rights or privileges?		
b	Admissions policies?		
c	Employment of faculty or administrative staff?		
d	Scholarships or other financial assistance?		
e	Educational policies?		
f	Use of facilities?		
g	Athletic programs?		
h	Other extracurricular activities?		
	If you answered "Yes" to any of the above, please explain. (If you need more space, attach a separate statement)		
34a	Does the organization receive any financial aid or assistance from a governmental agency?		
b	Has the organization's right to such aid ever been revoked or suspended? If you answered "Yes" to either 34a or b, please explain using an attached statement.		
35	Does the organization certify that it has complied with the applicable requirements of sections 4.01 through 4.05 of Rev. Proc. 75-50, 1975-2 C.B. 587, covering racial nondiscrimination? If "No," attach an explanation		

Part VI-A Lobbying Expenditures by Electing Public Charities (See page 9 of the instructions.)
(To be completed **ONLY** by an eligible organization that filed Form 5768)

Check **a** if the organization belongs to an affiliated group. Check **b** if you checked "a" and "limited control" provisions apply

Limits on Lobbying Expenditures		(a) Affiliated group totals	(b) To be completed for ALL electing organizations
(The term "expenditures" means amounts paid or incurred)			
36	Total lobbying expenditures to influence public opinion (grassroots lobbying)	36	
37	Total lobbying expenditures to influence a legislative body (direct lobbying).	37	
38	Total lobbying expenditures (add lines 36 and 37)	38	
39	Other exempt purpose expenditures	39	
40	Total exempt purpose expenditures (add lines 38 and 39)	40	
41	Lobbying nontaxable amount. Enter the amount from the following table— If the amount on line 40 is— The lobbying nontaxable amount is— Not over \$500,000 20% of the amount on line 40 Over \$500,000 but not over \$1,000,000 \$100,000 plus 15% of the excess over \$500,000 Over \$1,000,000 but not over \$1,500,000 \$175,000 plus 10% of the excess over \$1,000,000 Over \$1,500,000 but not over \$17,000,000. \$225,000 plus 5% of the excess over \$1,500,000 Over \$17,000,000. \$1,000,000	41	
42	Grassroots nontaxable amount (enter 25% of line 41).	42	
43	Subtract line 42 from line 36. Enter -0- if line 42 is more than line 36.	43	
44	Subtract line 41 from line 38. Enter -0- if line 41 is more than line 38.	44	

Caution: If there is an amount on either line 43 or line 44, you must file Form 4720.

4-Year Averaging Period Under Section 501(h)

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below.
See the instructions for lines 45 through 50 on page 11 of the instructions.)

	Lobbying Expenditures During 4-Year Averaging Period				
	(a) 2005	(b) 2004	(c) 2003	(d) 2002	(e) Total
45	Lobbying nontaxable amount				
46	Lobbying ceiling amount (150% of line 45(e))				
47	Total lobbying expenditures				
48	Grassroots nontaxable amount				
49	Grassroots ceiling amount (150% of line 48(e))				
50	Grassroots lobbying expenditures				

Part VI-B Lobbying Activity by Nonelecting Public Charities

(For reporting only by organizations that did not complete Part VI-A) (See page 11 of the instructions.)

During the year, did the organization attempt to influence national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:	Yes	No	Amount
a Volunteers		✓	
b Paid staff or management (Include compensation in expenses reported on lines c through h.)		✓	
c Media advertisements.		✓	
d Mailings to members, legislators, or the public		✓	
e Publications, or published or broadcast statements		✓	
f Grants to other organizations for lobbying purposes		✓	
g Direct contact with legislators, their staffs, government officials, or a legislative body.		✓	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any other means		✓	
i Total lobbying expenditures (Add lines c through h.)			0

If "Yes" to any of the above, also attach a statement giving a detailed description of the lobbying activities.

Statement 1
Form 990 EZ
Page 2
Part III
Question

22Q13 DELETION SYNDROME FOUNDATION
04-3673104

Program Services

Achievement	Pgm. Svc. Exp.
Held international conference for families in July 2004 in Greenville, SC Approximately 60 families attended to provide support and share information about this rare genetic condition	\$0 00
Grants and Allocations: \$0 00	
	Total: \$0.00

Statement 2
 Form 990 EZ
 Page 2
 Part IV
 Question

22Q13 DELETION SYNDROME FOUNDATION
 04-3673104

Officers, Directors, Trustees, and Key Employees

Name and Address	Title	Hrs	Comp.	Benefits	Expenses
Gail A Stapleton, M S , C G C 2 Doctors Drive Greenville, SC 29605-4265 United States	Treasurer	0	\$0 00	\$0 00	\$0 00
Katy Phelan, Ph D 250 East Broadway Maryville, TN 37804 United States	Board Member	0	\$0.00	\$0 00	\$0 00
Mary Pat O'Callaghan 3726 Dunn Avenue Lincoln, NE 68502 United States	Board Member	0	\$0.00	\$0 00	\$0 00
Nick Assendelft 34236 Kercheval Clinton Township, MI 48035 United States	Vice President	0	\$0 00	\$0 00	\$0.00
R Curtis Rogers, M D 2 Doctors Drive Greenville, SC 29605-4265 United States	Exec Director/CEO	0	\$0 00	\$0 00	\$0 00
Randy Riddle 5501 Vista Sandia Albuquerque, NM 87111 United States	Board Member	0	\$0.00	\$0 00	\$0 00
Rory Jones 27 Desjardins Court Hamilton, Ontario L8S 3R7 Canada	Secretary	0	\$0 00	\$0 00	\$0 00
Sue Macdonald-Lomas 830 Golf Drive Venice, FL 34285 United States	President	0	\$0 00	\$0 00	\$0 00
TOTALS			\$0.00	\$0.00	\$0.00