

Form **990-EZ**

**Short Form**  
**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)

**2004**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

▶ 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

**A For the 2004 calendar year, or tax year beginning January 01, 2004, and ending December 31, 20 04**

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

Please use IRS label or print or type See Specific Instructions

**C Name of organization**  
**22Q13 DELETION SYNDROME FOUNDATION**

Number and street (or P O box, if mail is not delivered to street address) Room/suite  
**2 Doctors Drive**

City or town, state or country, and ZIP + 4  
**Greenville SC 29605-4265**

**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** ) ◀ (insert no)  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 received a Form 990 Package in the mail, it should file a return without financial data. **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.** ▶ \$ **11068**

**Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances** (See page 37 of the instructions.)

		1	2	3	4	5a	5b	5c	6a	6b	6c	7a	7b	7c	8	9		
Revenue	1	Contributions, gifts, grants, and similar amounts received . . . . .															11068	
	2	Program service revenue including government fees and contracts . . . . .															0	
	3	Membership dues and assessments . . . . .															0	
	4	Investment income . . . . .															0	
	5a	Gross amount from sale of assets other than inventory . . . . .					0											
	5b	Less cost or other basis and sales expenses . . . . .					0											
	5c	Gain or (loss) from sale of assets other than inventory (line 5a less line 5b) (attach schedule).							0									
	6	Special events and activities (attach schedule) If any amount is from gaming, check here ▶ <input type="checkbox"/>																
	6a	Gross revenue (not including \$ <u>0</u> of contributions reported on line 1) . . . . .								0								
	6b	Less direct expenses other than fundraising expenses . . . . .								0								
6c	Net income or (loss) from special events and activities (line 6a less line 6b) . . . . .										0							
7a	Gross sales of inventory, less returns and allowances . . . . .								0									
7b	Less cost of goods sold . . . . .								0									
7c	Gross profit or (loss) from sales of inventory (line 7a less line 7b) . . . . .													0				
8	Other revenue (describe ▶ _____ )														0			
9	<b>Total revenue</b> (add lines 1, 2, 3, 4, 5c, 6c, 7c, and 8) . . . . . ▶																11068	
Expenses	10	Grants and similar amounts paid (attach schedule) . . . . .																
	11	Benefits paid to or for members . . . . .															5649	
	12	Salaries, other compensation, and employee benefits . . . . .															0	
	13	Professional fees and other payments to independent contractors . . . . .															350	
	14	Occupancy, rent, utilities, and maintenance . . . . .															0	
	15	Printing, publications, postage, and shipping . . . . .															1536	
	16	Other expenses (describe ▶ _____ )															0	
17	<b>Total expenses</b> (add lines 10 through 16) . . . . . ▶																7535	
Net Assets	18	Excess or (deficit) for the year (line 9 less line 17) . . . . .															3533	
	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return) . . . . .															4449	
	20	Other changes in net assets or fund balances (attach explanation) . . . . .																
	21	Net assets or fund balances at end of year (combine lines 18 through 20) . . . . . ▶																7982

**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

(See page 40 of the instructions)

		(A) Beginning of year	(B) End of year
22	Cash, savings, and investments . . . . .	4449	22 7982
23	Land and buildings . . . . .	0	23 0
24	Other assets (describe ▶ _____ )	0	24 0
25	<b>Total assets</b> . . . . .	4449	25 7982
26	<b>Total liabilities</b> (describe ▶ _____ )		26
27	<b>Net assets or fund balances</b> (line 27 of column (B) must agree with line 21) . . . . .	4449	27 7982

<b>Part III Statement of Program Service Accomplishments</b> (See page 41 of the instructions.)		<b>Expenses</b>	
What is the organization's primary exempt purpose? <b>Attachment #1: PRIMARY EXEMPT PURPOSE</b>		(Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts, optional for others)	
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			
<b>28</b>	<b>Attachment #2: PROGRAM SERVICE ACCOMPLISHMENTS</b> .....		
	(Grants \$ )	<b>28a</b>	
<b>29</b>	.....		
	(Grants \$ )	<b>29a</b>	
<b>30</b>	.....		
	(Grants \$ )	<b>30a</b>	
<b>31</b>	Other program services (attach schedule) . . . . . (Grants \$ )	<b>31a</b>	
<b>32</b>	<b>Total program service expenses</b> (add lines 28a through 31a) . . . . . ▶	<b>32</b>	<b>7535</b>

<b>Part IV List of Officers, Directors, Trustees, and Key Employees</b> (List each one even if not compensated. See page 41 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
<b>Attachment #3: OFFICERS</b>				
.....				
.....				
.....				

<b>Part V Other Information</b> (Note the attachment requirement in General Instruction V, page 14.)		Yes	No
<b>33</b>	Did the organization engage in any activity not previously reported to the IRS? If "Yes," attach a detailed description of each activity . . . . .		<input checked="" type="checkbox"/>
<b>34</b>	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 . . . . .		<input checked="" type="checkbox"/>
<b>35</b>	If the organization had income from business activities, such as those reported on lines 2, 6, and 7 (among others), but <b>not</b> reported on Form 990-T, attach a statement explaining your reason for not reporting the income on Form 990-T.		
<b>a</b>	Did the organization have unrelated business gross income of \$1,000 or more or 6033(e) notice, reporting, and proxy tax requirements? . . . . .		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," has it filed a tax return on <b>Form 990-T</b> for this year? . . . . .		
<b>36</b>	Was there a liquidation, dissolution, termination, or substantial contraction during the year? (If "Yes," attach a statement) . . . . .		<input checked="" type="checkbox"/>
<b>37a</b>	Enter amount of political expenditures, direct or indirect, as described in the instructions ▶ <b>37a</b>	0	
<b>b</b>	Did the organization file <b>Form 1120-POL</b> for this year? . . . . .		<input checked="" type="checkbox"/>
<b>38a</b>	Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee <b>or</b> were any such loans made in a prior year and still unpaid at the start of the period covered by this return? . . . . .		<input checked="" type="checkbox"/>
<b>b</b>	If "Yes," attach the schedule specified in the line 38 instructions and enter the amount involved <b>38b</b>	0	
<b>39</b>	<b>501(c)(7) organizations.</b> Enter <b>a</b> Initiation fees and capital contributions included on line 9 <b>39a</b>		
<b>b</b>	Gross receipts, included on line 9, for public use of club facilities <b>39b</b>		
<b>40a</b>	<b>501(c)(3) organizations</b> Enter Amount of tax imposed on the organization during the year under section 4911 ▶ <b>0</b> , section 4912 ▶ <b>0</b> , section 4955 ▶ <b>0</b>		
<b>b</b>	<b>501(c)(3) and (4) organizations.</b> 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 . . . . .		<input checked="" type="checkbox"/>
<b>c</b>	Amount of tax imposed on organization managers or disqualified persons during the year under 4912, 4955, and 4958 ▶		0
<b>d</b>	Enter Amount of tax on line 40c, above, reimbursed by the organization . . . . . ▶		0
<b>41</b>	List the states with which a copy of this return is filed ▶ <b>South Carolina</b>		
<b>42</b>	The books are in care of ▶ <b>Gail Stapleton</b> Telephone no ▶ <b>(864) 250-7944</b> Located at ▶ <b>2 Doctors Drive Greenville SC</b> ZIP + 4 ▶ <b>29605</b>		
<b>43</b>	<b>Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041</b> —Check here ▶ <input type="checkbox"/> and enter the amount of tax-exempt interest received or accrued during the tax year . . . ▶ <b>43</b>		

**Please Sign Here**

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.

Signature of officer: **Gail Stapleton, Treasurer** Date: **February 16, 2005**

Type or print name and title

**Paid Preparer's Use Only**

Preparer's signature: \_\_\_\_\_ Date: \_\_\_\_\_ Check if self-employed:

Firm's name (or yours if self-employed), address, and ZIP + 4: \_\_\_\_\_ Preparer's SSN or PTIN (See Gen. Inst. W): \_\_\_\_\_

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 Section 4947(a)(1) Nonexempt Charitable Trust

OMB No 1545-0047

**2004**

Department of the Treasury  
Internal Revenue Service

▶ **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

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

	Yes	No
<b>1</b> 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.	1	✓
<b>2</b> 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.)		
<b>a</b> Sale, exchange, or leasing of property? . . . . .	2a	✓
<b>b</b> Lending of money or other extension of credit? . . . . .	2b	✓
<b>c</b> Furnishing of goods, services, or facilities? . . . . .	2c	✓
<b>d</b> Payment of compensation (or payment or reimbursement of expenses if more than \$1,000)? . . . . .	2d	✓
<b>e</b> Transfer of any part of its income or assets? . . . . .	2e	✓
<b>3a</b> 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) . . . . .	3a	✓
<b>b</b> Do you have a section 403(b) annuity plan for your employees? . . . . .	3b	✓
<b>4a</b> Did you maintain any separate account for participating donors where donors have the right to provide advice on the use or distribution of funds? . . . . .	4a	✓
<b>b</b> Do you provide credit counseling, debt management, credit repair, or debt negotiation services? . . . . .	4b	✓

**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)** section 501(c)(4), (5), or (6), if they meet the test of section 509(a)(2) (See section 509(a)(3))

Provide the following information about the supported organizations (See page 5 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 5 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) 2003	(b) 2002	(c) 2001	(d) 2000	(e) Total
<b>15</b> Gifts, grants, and contributions received (Do not include unusual grants. See line 28).	4448	0	0	0	4448
<b>16</b> Membership fees received . . . . .	0	0	0	0	0
<b>17</b> 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
<b>18</b> 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
<b>19</b> Net income from unrelated business activities not included in line 18. . . . .	0	0	0	0	0
<b>20</b> Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf . . . . .	0	0	0	0	0
<b>21</b> 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
<b>22</b> Other income. Attach a schedule. Do not include gain or (loss) from sale of capital assets . . . . .	0	0	0	0	0
<b>23</b> Total of lines 15 through 22 . . . . .	4448	0	0	0	4448
<b>24</b> Line 23 minus line 17 . . . . .	4448	0	0	0	4448
<b>25</b> Enter 1% of line 23 . . . . .	44	0	0	0	

<b>26 Organizations described on lines 10 or 11:</b> a Enter 2% of amount in column (e), line 24 . . . . ▶	<b>26a</b>	
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 2000 through 2003 exceeded the amount shown in line 26a. Do not file this list with your return. Enter the total of all these excess amounts ▶	<b>26b</b>	
c Total support for section 509(a)(1) test. Enter line 24, column (e) . . . . . ▶	<b>26c</b>	
d Add Amounts from column (e) for lines 18 _____ 19 _____ 22 _____ 26b _____ . . . . . ▶	<b>26d</b>	
e Public support (line 26c minus line 26d total) . . . . . ▶	<b>26e</b>	
f Public support percentage (line 26e (numerator) divided by line 26c (denominator)) . . . . . ▶	<b>26f</b>	%

**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

(2003) \_\_\_\_\_ 0 (2002) \_\_\_\_\_ 0 (2001) \_\_\_\_\_ 0 (2000) \_\_\_\_\_ 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 11, 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

(2003) \_\_\_\_\_ 0 (2002) \_\_\_\_\_ 0 (2001) \_\_\_\_\_ 0 (2000) \_\_\_\_\_ 0

c Add Amounts from column (e) for lines 15 _____ 4448 16 _____ 0 17 _____ 0 20 _____ 0 21 _____ 0 . . . . . ▶	<b>27c</b>	4448
d Add Line 27a total, _____ 0 and line 27b total _____ 0 . . . . . ▶	<b>27d</b>	0
e Public support (line 27c total minus line 27d total) . . . . . ▶	<b>27e</b>	4448
f Total support for section 509(a)(2) test. Enter amount from line 23, column (e) . . . . ▶	<b>27f</b>	4448
g Public support percentage (line 27e (numerator) divided by line 27f (denominator)) . . . . . ▶	<b>27g</b>	1 %
h Investment income percentage (line 18, column (e) (numerator) divided by line 27f (denominator)) . . . . ▶	<b>27h</b>	0 %

**28 Unusual Grants:** For an organization described in line 10, 11, or 12 that received any unusual grants during 2000 through 2003, 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
<b>29</b>	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? . . . . .		
<b>30</b>	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? . . . . .		
<b>31</b>	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 ) ..... ..... .....		
<b>32</b>	Does the organization maintain the following		
<b>a</b>	Records indicating the racial composition of the student body, faculty, and administrative staff? . . . . .		
<b>b</b>	Records documenting that scholarships and other financial assistance are awarded on a racially nondiscriminatory basis? . . . . .		
<b>c</b>	Copies of all catalogues, brochures, announcements, and other written communications to the public dealing with student admissions, programs, and scholarships? . . . . .		
<b>d</b>	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 ) ..... .....		
<b>33</b>	Does the organization discriminate by race in any way with respect to		
<b>a</b>	Students' rights or privileges? . . . . .		
<b>b</b>	Admissions policies? . . . . .		
<b>c</b>	Employment of faculty or administrative staff? . . . . .		
<b>d</b>	Scholarships or other financial assistance? . . . . .		
<b>e</b>	Educational policies? . . . . .		
<b>f</b>	Use of facilities? . . . . .		
<b>g</b>	Athletic programs? . . . . .		
<b>h</b>	Other extracurricular activities? . . . . .		
	If you answered "Yes" to any of the above, please explain (If you need more space, attach a separate statement ) ..... .....		
<b>34a</b>	Does the organization receive any financial aid or assistance from a governmental agency? . . . . .		
<b>b</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		
<b>35</b>	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

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

**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)

Calendar year (or fiscal year beginning in) ▶	Lobbying Expenditures During 4-Year Averaging Period				
	(a) 2004	(b) 2003	(c) 2002	(d) 2001	(e) Total
<b>45</b> Lobbying nontaxable amount . . . . .					
<b>46</b> Lobbying ceiling amount (150% of line 45(e))					
<b>47</b> Total lobbying expenditures . . . . .					
<b>48</b> Grassroots nontaxable amount . . . . .					
<b>49</b> Grassroots ceiling amount (150% of line 48(e))					
<b>50</b> 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
<b>a</b> Volunteers . . . . .		✓	
<b>b</b> Paid staff or management (Include compensation in expenses reported on lines <b>c</b> through <b>h</b> ). . . . .		✓	
<b>c</b> Media advertisements . . . . .		✓	
<b>d</b> Mailings to members, legislators, or the public . . . . .		✓	
<b>e</b> Publications, or published or broadcast statements . . . . .		✓	
<b>f</b> Grants to other organizations for lobbying purposes . . . . .		✓	
<b>g</b> Direct contact with legislators, their staffs, government officials, or a legislative body. . . . .		✓	
<b>h</b> Rallies, demonstrations, seminars, conventions, speeches, lectures, or any other means . . . . .		✓	
<b>i</b> Total lobbying expenditures (Add lines <b>c</b> through <b>h</b> ). . . . .			<b>0</b>

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



Attention: This page was created using data from an Electronically-Filed return.

**Organization Name:** 22Q13 DELETION SYNDROME FOUNDATION

**EIN:** 04-3673104

Return: 990EZ

PRIMARY EXEMPT PURPOSE

Statement: 1

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Help families who have a child with the 22q13 deletion syndrome

**Organization Name:** 22Q13 DELETION SYNDROME FOUNDATION

**EIN:** 04-3673104

Return: 990EZ

Program Service Accomplishments

Statement: 2

Page 1 of 1

Grants: 0

Expenses: 7535

Description:

**Disease, Disorders, Medical Disciplines: 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. -60 Families-**

EIN: 04-3673104

**Organization Name: 22Q13 DELETION SYNDROME FOUNDATION**

Return: 990EZ

Statement: 3

**OFFICERS, DIRECTORS, TRUSTEES, AND KEY EMPLOYEES**

Page 1 of 2

Name	Gail A Stapleton Ms Cgc	Hours/ week	8	Compensation	0	Contributions to Benefit Plans	0	Expense Account	0
Title:	Treasurer								
Address:	2 Doctors Drive Greenville SC 29605-4265								
Name	Katy Phelan Phd	Hours/ week	8	Compensation	0	Contributions to Benefit Plans	0	Expense Account	0
Title:	Board Member								
Address:	250 East Broadway Maryville TN 37804								
Name	Randy Riddle	Hours/ week	3	Compensation	0	Contributions to Benefit Plans	0	Expense Account	0
Title:	Board Member								
Address:	5501 Vista Sandia Albuquerque NM 87111								
Name	R Curtis Rogers Md	Hours/ week	1	Compensation	0	Contributions to Benefit Plans	0	Expense Account	0
Title:	Exec Director/CEO								
Address:	2 Doctors Drive Greenville SC 29605-4265								
Name	Sue Macdonaldlomas	Hours/ week	8	Compensation	0	Contributions to Benefit Plans	0	Expense Account	0
Title:	President								
Address:	830 Golf Drive Venice FL 34285								
Name	Nick Assendelft	Hours/ week	8	Compensation	0	Contributions to Benefit Plans	0	Expense Account	0
Title:	Vice President								
Address:	34236 Kercheval Clinton Township MI 48035								

**Organization Name: 22Q13 DELETION SYNDROME FOUNDATION**

**EIN: 04-3673104**

Return: 990EZ

Statement: 3

**OFFICERS, DIRECTORS, TRUSTEES, AND KEY EMPLOYEES**

Page 2 of 2

Name **Rory Jones** Hours/week **2** Compensation **0** Contributions to Benefit Plans **0** Expense Account **0**  
Title: **Secretary**

Address: **27 Desjardins Court Hamilton Ontario L8S 3R7 Canada**

Name **Mary Pat OCallaghan** Hours/week **3** Compensation **0** Contributions to Benefit Plans **0** Expense Account **0**  
Title: **Board Member**

Address: **3726 Dunn Avenue Lincoln NE 68502**

Name \_\_\_\_\_ Hours/week \_\_\_\_\_ Compensation \_\_\_\_\_ Contributions to Benefit Plans \_\_\_\_\_ Expense Account \_\_\_\_\_  
Title: \_\_\_\_\_

Address: \_\_\_\_\_

Name \_\_\_\_\_ Hours/week \_\_\_\_\_ Compensation \_\_\_\_\_ Contributions to Benefit Plans \_\_\_\_\_ Expense Account \_\_\_\_\_  
Title: \_\_\_\_\_

Address: \_\_\_\_\_

Name \_\_\_\_\_ Hours/week \_\_\_\_\_ Compensation \_\_\_\_\_ Contributions to Benefit Plans \_\_\_\_\_ Expense Account \_\_\_\_\_  
Title: \_\_\_\_\_

Address: \_\_\_\_\_

Name \_\_\_\_\_ Hours/week \_\_\_\_\_ Compensation \_\_\_\_\_ Contributions to Benefit Plans \_\_\_\_\_ Expense Account \_\_\_\_\_  
Title: \_\_\_\_\_

Address: \_\_\_\_\_

**Organization Name:** 22Q13 DELETION SYNDROME FOUNDATION

**EIN:** 04-3673104

Return: 990EZ

COMPENSATION EXPLANATION

Statement: 4

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COMPENSATION NAME

EXPLANATION

Gail A Stapleton MS CGC

Katy Phelan PhD

Randy Riddle

R Curtis Rogers MD

Sue MacdonaldLomas

Nick Assendelft

Rory Jones

Mary Pat OCallaghan