



# Families of SMA

## FAMILIES OF SPINAL MUSCULAR ATROPHY

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FINANCIAL STATEMENTS

JUNE 30, 2013 AND 2012

AND REPORT ON COMPLIANCE

JUNE 30, 2013

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## **INDEPENDENT AUDITORS' REPORT**

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Families of Spinal Muscular Atrophy  
Elk Grove Village, Illinois

We have audited the accompanying financial statements of Families of Spinal Muscular Atrophy, which comprise the statements of financial position as of June 30, 2013 and 2012, and the related statements of activities and cash flows for the years then ended, and the related notes to the financial statements.

### *Management's Responsibility for the Financial Statements*

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

### *Auditor's Responsibility*

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America and the standards applicable to financial audits contained in *Government Auditing Standards*, issued by the Comptroller General of the United States. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.



### *Opinion*

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Families of Spinal Muscular Atrophy as of June 30, 2013 and 2012, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

### *Report on Supplementary Information*

Our audits were conducted for the purpose of forming an opinion on the financial statements as a whole. The schedules of functional expenses are presented for purposes of additional analysis and are not a required part of the financial statements. The accompanying schedule of expenditures of federal awards, as required by Office of Management and Budget Circular A-133, *Audits of States, Local Governments, and Non-Profit Organizations* is presented for purposes of additional analysis and is not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audit of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the supplementary information is fairly stated, in all material respects, in relation to the financial statements as a whole.

### *Other Reporting Required by Government Auditing Standards*

In accordance with *Government Auditing Standards*, we have also issued our report dated October 21, 2013, on our consideration of Families of Spinal Muscular Atrophy's internal control over financial reporting and on our tests of its compliance with certain provisions of laws, regulations, contracts, and grant agreements. The purpose of that report is to describe the scope of our testing of internal control over financial reporting and compliance and the results of that testing, and not to provide an opinion on internal control over financial reporting or on compliance. That report is an integral part of an audit performed in accordance with *Government Auditing Standards* in considering Families of Spinal Muscular Atrophy's internal control over financial reporting and compliance.

A handwritten signature in black ink that reads "KPMG, Rossin & Co." The signature is written in a cursive, flowing style.

October 21, 2013  
Miami, Florida

**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**STATEMENTS OF FINANCIAL POSITION**  
**JUNE 30, 2013 AND 2012**

<b>ASSETS</b>	<b>2013</b>	<b>2012</b>
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 2,618,662	\$ 1,991,069
Pledges receivable	149,349	222,704
Other current assets	61,287	28,567
Total current assets	2,829,298	2,242,340
RESTRICTED CASH (NOTES 2 AND 6)	30,000	220,438
ENDOWMENT FUND (NOTES 2 AND 6)	406,946	-
INVESTMENT - PRIVATE COMPANY STOCK (NOTE 3)	36,461	36,461
PROPERTY AND EQUIPMENT (NOTE 4)	136,594	95,095
	\$ 3,439,299	\$ 2,594,334
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and accrued expenses	\$ 389,641	\$ 428,023
Grants payable (Note 5)	899,562	463,647
Total current liabilities	1,289,203	891,670
GRANTS PAYABLE (NOTE 5)	105,000	82,000
COMMITMENTS AND CONTINGENCIES (NOTE 8)		
NET ASSETS (NOTE 6)		
Unrestricted	1,104,164	1,257,728
Temporarily restricted	533,986	142,498
Permanently restricted	406,946	220,438
Total net assets	2,045,096	1,620,664
	\$ 3,439,299	\$ 2,594,334

See accompanying notes.

**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**STATEMENT OF ACTIVITIES**  
**YEAR ENDED JUNE 30, 2013**

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
<b>PUBLIC SUPPORT AND OTHER INCOME</b>				
Contributions and event related revenue (Note 2)	\$ 4,129,877	\$ 567,721	\$ 184,976	\$ 4,882,574
Other income	335,722	-	-	335,722
Interest income (Note 2)	859	-	1,532	2,391
Net assets released from restrictions	176,233	( 176,233)	-	-
<b>Total public support and other income</b>	<b>4,642,691</b>	<b>391,488</b>	<b>186,508</b>	<b>5,220,687</b>
<b>EXPENSES</b>				
Program Services:				
Research (Note 5)	1,869,970	-	-	1,869,970
Patient services	615,475	-	-	615,475
Family support	579,031	-	-	579,031
Awareness	215,276	-	-	215,276
<b>Total program services</b>	<b>3,279,752</b>	<b>-</b>	<b>-</b>	<b>3,279,752</b>
Supporting Services:				
General and administrative	230,348	-	-	230,348
Fundraising and event related	1,286,155	-	-	1,286,155
<b>Total supporting services</b>	<b>1,516,503</b>	<b>-</b>	<b>-</b>	<b>1,516,503</b>
<b>Total expenses</b>	<b>4,796,255</b>	<b>-</b>	<b>-</b>	<b>4,796,255</b>
<b>CHANGE IN NET ASSETS</b>	<b>( 153,564)</b>	<b>391,488</b>	<b>186,508</b>	<b>424,432</b>
<b>NET ASSETS - BEGINNING</b>	<b>1,257,728</b>	<b>142,498</b>	<b>220,438</b>	<b>1,620,664</b>
<b>NET ASSETS - ENDING</b>	<b>\$ 1,104,164</b>	<b>\$ 533,986</b>	<b>\$ 406,946</b>	<b>\$ 2,045,096</b>

See accompanying notes.

**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**STATEMENT OF ACTIVITIES**  
**YEAR ENDED JUNE 30, 2012**

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
<b>PUBLIC SUPPORT AND OTHER INCOME</b>				
Contributions and event related revenue	\$ 3,824,355	\$ 562,067	\$ -	\$ 4,386,422
Other income	241,690	-	-	241,690
Interest income and investment activity, net	2,149	-	-	2,149
Transfers (Note 6)	-	( 220,438)	220,438	-
Net assets released from restrictions	288,807	( 288,807)	-	-
<b>Total public support and other income</b>	<b>4,357,001</b>	<b>52,822</b>	<b>220,438</b>	<b>4,630,261</b>
<b>EXPENSES</b>				
Program Services:				
Research (Note 5)	1,507,602	-	-	1,507,602
Patient services	386,180	-	-	386,180
Family support	546,378	-	-	546,378
Awareness	121,372	-	-	121,372
<b>Total program services</b>	<b>2,561,532</b>	<b>-</b>	<b>-</b>	<b>2,561,532</b>
Supporting Services:				
General and administrative	184,660	-	-	184,660
Fundraising and event related	1,099,079	-	-	1,099,079
<b>Total supporting services</b>	<b>1,283,739</b>	<b>-</b>	<b>-</b>	<b>1,283,739</b>
<b>Total expenses</b>	<b>3,845,271</b>	<b>-</b>	<b>-</b>	<b>3,845,271</b>
<b>CHANGE IN NET ASSETS</b>	<b>511,730</b>	<b>52,822</b>	<b>220,438</b>	<b>784,990</b>
<b>NET ASSETS - BEGINNING</b>	<b>745,998</b>	<b>89,676</b>	<b>-</b>	<b>835,674</b>
<b>NET ASSETS - ENDING</b>	<b>\$ 1,257,728</b>	<b>\$ 142,498</b>	<b>\$ 220,438</b>	<b>\$ 1,620,664</b>

See accompanying notes.

**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**STATEMENTS OF CASH FLOWS**  
**YEARS ENDED JUNE 30, 2013 AND 2012**

	<b>2013</b>	2012
<b>CASH FLOWS FROM OPERATING ACTIVITIES:</b>		
Change in net assets	\$ 424,432	\$ 784,990
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation	34,178	20,998
Net realized and unrealized losses on investments	-	85
Contributions restricted for investment in endowment fund	( 186,508)	-
Changes in operating assets and liabilities:		
Pledges receivable	73,355	( 113,017)
Other current assets	( 32,720)	6,575
Accounts payable and accrued expenses	( 38,382)	( 20,275)
Grants payable	458,915	150,285
Total adjustments	308,838	44,651
Net cash provided by operating activities	733,270	829,641
<b>CASH FLOWS FROM INVESTING ACTIVITIES:</b>		
Capital expenditures	( 75,677)	( 45,382)
Net proceeds from sales of investments	-	2,532
Restricted cash	190,438	( 220,438)
Investment in endowment fund	( 406,946)	-
Net cash used in investing activities	( 292,185)	( 263,288)
<b>CASH FLOWS FROM FINANCING ACTIVITIES:</b>		
Contributions restricted for investment in endowment	186,508	-
<b>NET INCREASE IN CASH AND CASH EQUIVALENTS</b>	<b>627,593</b>	<b>566,353</b>
<b>CASH AND CASH EQUIVALENTS - BEGINNING</b>	<b>1,991,069</b>	<b>1,424,716</b>
<b>CASH AND CASH EQUIVALENTS - ENDING</b>	<b>\$ 2,618,662</b>	<b>\$ 1,991,069</b>
<b>Supplemental Disclosure of Cash Flow Information:</b>		
Interest paid	\$ -	\$ -
Income taxes paid	\$ -	\$ -

See accompanying notes.



**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**NOTES TO FINANCIAL STATEMENTS**

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**NOTE 1. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES**

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*Organization and Purpose*

Families of Spinal Muscular Atrophy (the “Organization”) is a not-for-profit organization that is tax-exempt under the provisions of Internal Revenue Code 501(c)(3). The purpose of the Organization is to raise money for advancing research, to provide patient and family support, and to promote public awareness with regard to the diseases Spinal Muscular Atrophy Type 1, Type 2 and Type 3.

*Basis of Presentation*

The financial statements of the Organization have been prepared on the accrual basis of accounting. Net assets, revenues, expenses, gains and losses are classified based on the existence or absence of donor-imposed restrictions as follows:

- *Unrestricted* - net assets that are not subject to donor-imposed restrictions.
- *Temporarily restricted* - net assets subject to donor-imposed restrictions that may or will be met by actions of the Organization or that expire by the passage of time.
- *Permanently restricted* - net assets subject to donor-imposed restrictions that require the assets be maintained permanently by the Organization.

*Restricted and Unrestricted Revenue and Support*

Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence and/or nature of any donor restrictions. Support that is restricted by the donor is reported as an increase in unrestricted net assets if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires (i.e. when a stipulated time restriction ends or purpose restriction is accomplished), restricted net assets are reclassified to unrestricted net assets and reported in the statements of activities as net assets released from restrictions.

*Cash and Cash Equivalents*

Cash and cash equivalents include highly liquid short-term investments with remaining maturities at date of purchase of three months or less. Cash equivalents include investments in money market funds that are carried at cost plus accrued interest, which approximates fair value.

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**NOTE 1. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

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***Investments***

The Organization's investments are reported at their fair values in the statements of financial position. Investment return, including realized and unrealized gains and losses, and interest and dividend income are included as a change in net assets in the statements of activities. Market risk is inherent and is dependent on the future changes in market prices of the investments held.

***Fair Value Measurements***

Fair value is defined as the price that the Organization would receive to sell an asset or pay to transfer a liability in an orderly transaction with an independent counterparty in the principal market or in the absence of a principal market, the most advantageous market for the asset or liability. Fair value is measured under a three-tier hierarchy to distinguish between (1) inputs that reflect the assumptions market participants would use in pricing an asset or liability developed based on market data obtained from sources independent of the reporting entity (observable inputs) and (2) inputs that reflect the reporting entity's own assumptions about the assumptions market participants would use in pricing an asset or liability developed based on the best information available in the circumstances (unobservable inputs) and to establish a classification of fair value measurements for disclosure purposes.

Various inputs are used in determining the value of the Organization's assets and liabilities. The inputs are summarized in the three broad levels listed below.

**Level 1** - quoted prices in active markets for identical assets or liabilities

**Level 2** - other significant observable inputs (including quoted prices for similar assets or liabilities, interest rates, credit risk, etc.)

**Level 3** - significant unobservable inputs (including the Organization's own assumptions in determining the fair value of assets or liabilities)

In applying the provisions of fair value measurements to the Organization's assets during the year, the following valuation techniques have been employed:

***Private Company Stock***

The Organization holds shares in a privately held company that specializes in alternative investment management. The underlying assets of the company primarily consist of direct private equity investments. The private company's fair value measurement is determined by its estimated value per share. Actual results may differ and could significantly affect the accuracy of the fair value estimate included in these financial statements. The Organization's ability to redeem the investment is restricted or uncertain in the near term. The Organization's investment in private company stock is categorized in Level 3 of the fair value hierarchy.

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**NOTE 1. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

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***Pledges Receivable***

Unconditional pledges receivable that are expected to be collected within one year are recorded at net realizable value. Unconditional pledges receivable that are expected to be collected in future years are recorded at fair value, using present value techniques and applicable discount rates. The discounts on the estimated future cash flows of pledges receivable are computed using risk-free interest rates applicable to the years in which the pledges are received. Amortization of the discount is included in contribution revenue. An allowance for uncollectible pledges receivable is provided based upon management's judgment, including such factors as prior collection history, type of contribution and nature of fund raising activity. After all attempts to collect a receivable have failed, the receivable is written off against the allowance.

As of June 30, 2013 and 2012, pledges receivable amounted to approximately \$149,000 and \$223,000, respectively, and pledges receivable from four and five donors accounted for approximately 97% and 95% of pledges receivable, respectively. No allowance was deemed necessary by management in either period.

Conditional pledges to give are not included as support until the conditions are substantially met. As of June 30, 2013, conditional pledges to give to the Organization are estimated to be \$225,000.

***Property and Equipment***

Property and equipment is recorded at cost, if purchased, and donated property is stated at fair market value at the date of contribution. Expenditures for major betterments and additions are charged to the asset accounts while replacements, maintenance and repairs, which do not improve or extend the lives of the respective assets, are charged to expense currently.

Depreciation of property and equipment is determined using the straight-line method, based on estimated useful lives of 3 to 7 years.

***Functional Expenses***

The costs of providing the Organization's various programs and other activities have been summarized on a functional basis. Direct costs are allocated specifically to the Organization's program and supporting services. Indirect costs are allocated by management to program and supporting services benefited based on the percentage of employee time spent among other factors. The allocation of costs is based on management's estimate.

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**NOTE 1. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

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***Advertising and Promotion***

Advertising and promotion costs are primarily related to fundraising events and press releases. These costs are expensed as incurred. For the years ended June 30, 2013 and 2012, advertising and promotion expense amounted to approximately \$81,000 and \$75,000, respectively, and is included as a component of program and supporting services in the accompanying statements of activities.

***Concentration of Credit Risk***

The Organization deposits excess cash with high credit quality financial institutions. At times, such balances may be in excess of federally insured limits.

***Contributed Services***

A substantial number of unpaid volunteers have made contributions of their time in connections with activities of the Organization. The value of this contributed time is not reflected in the financial statements since it is not susceptible to objective measurement or valuation.

***Income Taxes***

The Organization has been granted an exemption from income taxes under Internal Revenue Code Section 501(c)(3) as a non-profit corporation. Certain activities not directly related to the Organization's tax-exempt purpose could be subject to taxation as unrelated business income, however a provision for unrelated business income tax was not required.

The Organization assesses its tax positions in accordance with "Accounting for Uncertainty in Income Taxes," as prescribed by Accounting Standards Codification, which provides guidance for financial statement recognition and measurement of uncertain tax positions taken or expected to be taken in a tax return for open tax years (generally a period of three years from the later of each return's due date or the date filed) that remain subject to examination by the Organization's major tax jurisdictions. Generally, the Organization is no longer subject to income tax examinations by major taxing authorities for years ending before June 30, 2010.

The Organization assesses its tax positions and determines whether it has any material unrecognized liabilities for uncertain tax positions. The Organization records these liabilities to the extent it deems them more likely than not to be incurred. Interest and penalties related to uncertain tax positions, if any, would be classified as a component of income tax expense.

The Organization believes that it does not have any significant uncertain tax positions requiring recognition or measurement in the accompanying financial statements.

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**NOTE 1. ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**

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***Use of Estimates in the Preparation of Financial Statements***

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities as of the statement of financial position dates and the reported amounts of revenues and expenses during the reporting periods. Actual results could differ from those estimates.

***Reclassification***

Certain amounts in the 2012 financial statements have been reclassified to conform with 2013 presentation, primarily related to program services in the supplementary schedules of functional expenses being expanded from two categories to four categories.

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**NOTE 2. ENDOWMENT**

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The Organization maintains an endowment fund consisting of gifts restricted by donors and the board of directors for permanent investment. The Organization follows the Illinois Uniform Prudent Management of Institutional Funds Act (IUPMIFA) and its own governing documents. IUPMIFA requires the Organization to prudently manage its endowment fund. The majority of the Organization's endowment contributions are subject to a specific agreement with the Organization.

The Organization entered into an agreement with a donor to establish an endowment fund for the purpose of providing scholarships to attend the Organization's annual conference for any families of patients new diagnosed with Spinal Muscular Atrophy. The agreement requires the following: (a) all earnings of the endowment fund are reinvested into the corpus of the endowment, (b) no withdrawals from the endowment fund are allowed if the fund balance is less than \$1,000,000, (c) up to 2.5% of the fund may be withdrawn, if the fund balance is above \$1,000,000 but less than \$2,000,000, so long as such withdrawal does not reduce the fund balance below \$1,000,000, (d) up to 5% of the fund may be withdrawn, if the fund balance is above \$2,000,000. Additionally, under the terms of the agreement, the board of directors designated \$30,000 of unrestricted net assets for the endowment fund.

The Organization's investment guidelines and policies are overseen by members of the finance committee reporting to the Organization's board of directors. The overall investment objective of the Organization is to maximize the return on invested assets while minimizing risk and expenses. This is done through prudent investing and planning, as well through the maintenance of a diversified portfolio. Investments shall be diversified with a view to minimizing risk. Investments in the equity securities of any one company shall not exceed 5% of the portfolio nor shall the total securities position (debt and equity) in any one company exceed 10% of the portfolio. No more than 25% of the entire portfolio may be invested in the securities of any one sector. The assets of the Organization have a long investment time horizon.

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**NOTE 2. ENDOWMENT (Continued)**

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The primary investment objective of the portfolio is to grow the corpus in excess of inflation and to meet the current and future obligations as dictated by the Organization's spending objectives. This objective is to be achieved through the establishment of an optimal portfolio structure and through the retention of quality investment managers capable of meeting the specific performance goals of the Organization. The investment portfolio is expected to achieve the following over rolling five year periods: (a) provide an annualized rate of return that will support the spending policy net of inflation, (b) outperform the return of a hypothetical portfolio composed of indexes weighted according to the target allocation, (c) outperform the median manager in a universe of foundations and endowments, (d) the volatility of returns, as measured by the standard deviation of quarterly returns, should be comparable to that of the benchmark index.

During the year ended June 30, 2013, the endowment fund was funded by establishing a money market account with a financial institution. As of June 30, 2013, the \$30,000 of board designated unrestricted net assets has not been transferred to the money market account and is reflected as restricted cash in the accompanying statements of financial position. Once the money market account reaches \$500,000, the Organization plans to transfer the funds to a diversified investment portfolio that will be managed by a third party investment manager.

Endowment net asset composition by type of fund as of June 30, 2013 is as follows:

	Unrestricted	Permanently restricted	Total
Board-restricted endowment funds	\$ 30,000	\$ -	\$ 30,000
Donor-restricted endowment funds	-	406,946	406,946
Total funds	\$ 30,000	\$ 406,946	\$ 436,946

Changes in endowment net assets for the year ended June 30, 2013 are as follows:

	Unrestricted	Permanently restricted	Total net endowment assets
Endowment net assets, beginning of year	\$ -	\$ -	\$ -
Prior year contributions transferred	30,000	220,438	250,438
Contributions	-	184,976	184,976
Investment income	-	1,532	1,532
Endowment net assets, end of year	\$ 30,000	\$ 406,946	\$ 436,946

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**NOTE 3. FAIR VALUE MEASUREMENT**


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The Organization's investments recorded at fair value have been categorized based upon a fair value hierarchy in accordance with the Organization's accounting policies as disclosed in Note 1.

The following table presents information about the Organization's assets measured at fair value for the years ended June 30, 2013 and 2012:

<b>ASSETS at fair value</b>	Quoted prices in active markets for identical assets (Level 1)	Significant other observable inputs (Level 2)	Significant unobservable inputs (Level 3)	Total
Private company stock	\$ -	\$ -	\$ 36,461	\$ 36,461

The following table presents additional information about Level 3 assets measured at fair value. Both observable and unobservable inputs may be used to determine the fair value of positions that the Organization has classified within the Level 3 category. As a result, the unrealized gains and losses for assets within the Level 3 category may include changes in fair value that were attributable to both observable and unobservable inputs.

Changes in Level 3 assets measured at fair value for the years ended June 30, 2013 and 2012 are as follows:

<b>ASSETS, at fair value</b>	Beginning balance	Purchases / Sales	Net unrealized gains (losses)	Ending balance
Private company stock	\$ 36,461	\$ -	\$ -	\$ 36,461

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**NOTE 4. PROPERTY AND EQUIPMENT**

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Property and equipment as of June 30 consisted of the following:

	<b>2013</b>	2012
Medical equipment	\$ 338,878	\$ 265,324
Office equipment	50,746	48,621
Office furniture	36,744	36,744
	426,368	350,689
Less: accumulated depreciation	( 289,774)	( 255,594)
	\$ 136,594	\$ 95,095

Depreciation expense for the years ended June 30, 2013 and 2012, amounted to approximately \$34,000 and \$21,000, respectively.

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**NOTE 5. GRANTS PAYABLE**

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The Organization makes grants to various medical and research centers for research in relation to Spinal Muscular Atrophy. Grant agreements are subject to periodic reporting and compliance requirements and can be rescinded by the Organization if it is determined that a research project is no longer academically, technically or commercially feasible. The Organization is responsible for all costs incurred or committed at the time of a research projects' termination. Research grant expense for the years ended June 30, 2013 and 2012, amounted to approximately \$1,233,000 and \$1,027,000, respectively, and is included as a component of research in the accompanying statements of activities.

As of June 30, 2013, the Organization's grants payable obligations have terms expiring through November 2014. As of June 30, 2013 and 2012, grants payable obligations amounted to approximately \$1,005,000 and \$546,000, respectively.

Certain grant payments are made to grantees based on research milestones being met. These obligations are not accrued since conditional promises to give are not recognized until the conditions are substantially met. At June 30, 2013, the timing of the research and development milestones being met and certainty of future grant payments is not readily determinable.

As of June 30, 2013, future conditional promises due to grantees based on the achievement of milestones are estimated to be \$730,000.



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**NOTE 6. NET ASSET RESTRICTIONS AND TRANSFERS**

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At June 30, 2013 and 2012, temporarily restricted net assets amounted to approximately \$534,000 and \$142,000 respectively, and are primarily restricted for research grants.

At June 30, 2013 and 2012, permanently restricted net assets amounted to approximately \$407,000 and \$220,000, respectively, and are restricted for a scholarship fund endowment. During the year ended June 30, 2012, approximately \$220,000 was transferred from temporarily restricted to permanently restricted due to the donors' intent to establish the scholarship fund endowment.

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**NOTE 7. CHAPTERS**

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The Organization has established Chapters consisting of volunteers who promote local and regional fund-raising and outreach efforts for the Organization by hosting events in their respective states and regions. As of June 30, 2013, there are thirty-one active chapters throughout the United States. Fund-raising and patient service support activities are coordinated by the staff of the Organization and revenue and expenses related to all such activities are included in the accompanying statements of activities.

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**NOTE 8. COMMITMENTS AND CONTINGENCIES**

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***Economic Conditions***

The Organization depends substantially on contributions for its revenues. The ability of certain Organization contributors to continue giving amounts comparable with prior years may be dependent upon current and future overall economic conditions. While the Organization's board of directors believes the Organization has the resources to continue its programs, its ability to do so and the extent to which it continues, may be dependent on the above factors.

***Lease Commitments***

The Organization leases office space for its headquarters located in Elk Grove Village, Illinois, expiring February 2017. The approximate future minimum lease payments under the non-cancelable operating lease are summarized below:

2014	\$	49,000
2015		50,000
2016		53,000
2017		35,000
		<hr/>
	\$	187,000

Rent expense, including common area maintenance costs, for the years ended June 30, 2013 and 2012 amounted to approximately \$62,000 and \$75,000, respectively.

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**NOTE 8. COMMITMENTS AND CONTINGENCIES (Continued)**

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***Licensing Agreements***

During 2010, the Organization entered into an Exclusive License Agreement with a biopharmaceutical company (the “Sublicensee”) to develop and commercialize certain licensed products potentially useful in the treatment of Spinal Muscular Atrophy, based on patent rights owned by the Organization. Under the terms of the agreement, the Organization is eligible to receive payments based on the achievement of certain milestone events as set forth in the agreement. During the years ended June 30, 2013 and 2012, the Organization did not receive any milestone payments related to this agreement. As of June 30, 2013, the Organization is eligible to receive up to \$11,250,000 in milestone payments from the Sublicensee.

Based on the nature of the development and commercialization process the timing and certainty of future contractual cash receipts cannot be determined at this time.

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**NOTE 9. SUBSEQUENT EVENTS**

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The Organization has evaluated subsequent events through October 21, 2013, which is the date the accompanying financial statements were available to be issued.

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**SUPPLEMENTARY INFORMATION  
AND REPORT ON COMPLIANCE**

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**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**SCHEDULE OF FUNCTIONAL EXPENSES**  
**YEAR ENDED JUNE 30, 2013**

	Program Services				Supporting Services				Total
	Research	Patient Services	Family Support	Awareness	Total Program Services	General and Administrative	Fund Raising and Event Related	Total Supporting Services	
<b>SALARIES AND RELATED</b>									
Salaries	\$ 172,802	\$ 124,196	\$ 248,413	\$ 74,182	\$ 619,593	\$ 105,644	\$ 282,049	\$ 387,693	\$ 1,007,286
Payroll taxes	12,148	8,587	15,611	3,788	40,134	6,864	35,984	42,848	82,982
Total salaries and related expenses	184,950	132,783	264,024	77,970	659,727	112,508	318,033	430,541	1,090,268
<b>NON-PERSONNEL EXPENSES:</b>									
Research grants	1,232,668	-	-	-	1,232,668	-	-	-	1,232,668
Fundraising events	12,601	11,178	20,531	27,667	71,977	13,320	664,347	677,667	749,644
Fundraising events - in kind	-	-	-	-	-	-	80,917	80,917	80,917
Conferences and meetings	260,133	155,164	109,987	21,280	546,564	79	4,801	4,880	551,444
Conferences and meetings - in kind	20,290	8,116	8,116	4,058	40,580	-	-	-	40,580
Professional fees	36,183	165,564	57,928	29,532	289,207	35,840	28,758	64,598	353,805
Advisory services	81,021	19,560	19,560	16,693	136,834	16,729	19,943	36,672	173,506
Merchandise	-	-	-	-	-	-	29,667	29,667	29,667
Postage and delivery	7,964	32,427	31,257	3,238	74,886	5,634	21,654	27,288	102,174
Website	466	811	811	258	2,346	25	4,995	5,020	7,366
Office	4,260	4,775	4,393	4,259	17,687	6,309	6,496	12,805	30,492
Insurance	4,723	11,755	18,699	4,680	39,857	5,325	17,727	23,052	62,909
Rent	10,367	10,367	10,367	10,367	41,468	10,367	10,367	20,734	62,202
Bank and credit card fees	-	-	-	-	-	3,814	55,559	59,373	59,373
Public relations	7,145	6,627	6,682	7,997	28,451	7,036	6,633	13,669	42,120
Miscellaneous	804	772	959	683	3,218	6,817	1,623	8,440	11,658
Telephone	2,500	2,458	2,458	2,458	9,874	2,550	2,575	5,125	14,999
Utilities	1,921	1,921	1,921	1,992	7,755	1,851	1,921	3,772	11,527
Miscellaneous patient services	-	27,740	19,194	-	46,934	-	7,824	7,824	54,758
Total non-personnel expenses	1,683,046	459,235	312,863	135,162	2,590,306	115,696	965,807	1,081,503	3,671,809
Total expenses before depreciation	1,867,996	592,018	576,887	213,132	3,250,033	228,204	1,283,840	1,512,044	4,762,077
Depreciation	1,974	23,457	2,144	2,144	29,719	2,144	2,315	4,459	34,178
Total expenses	\$ 1,869,970	\$ 615,475	\$ 579,031	\$ 215,276	\$ 3,279,752	\$ 230,348	\$ 1,286,155	\$ 1,516,503	\$ 4,796,255

See independent auditors' report.

**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**SCHEDULE OF FUNCTIONAL EXPENSES**  
**YEAR ENDED JUNE 30, 2012**

	Program Services				Supporting Services				
	Research	Patient Services	Family Support	Awareness	Total Program Services	General and Administrative	Fund Raising and Event Related	Total Supporting Services	Total
<b>SALARIES AND RELATED</b>									
Salaries	\$ 148,548	\$ 88,590	\$ 207,349	\$ 40,672	\$ 485,159	\$ 81,426	\$ 330,093	\$ 411,519	\$ 896,678
Payroll taxes	11,356	6,335	13,710	2,729	34,130	6,497	32,126	38,623	72,753
Total salaries and related expenses	159,904	94,925	221,059	43,401	519,289	87,923	362,219	450,142	969,431
<b>NON-PERSONNEL EXPENSES:</b>									
Research grants	1,027,418	-	-	-	1,027,418	-	-	-	1,027,418
Fundraising events	1,362	-	5,538	-	6,900	1,246	560,829	562,075	568,975
Conferences and meetings	154,986	37,255	153,612	6,832	352,685	-	3,182	3,182	355,867
Professional fees	79,247	111,769	68,570	31,047	290,633	31,615	20,443	52,058	342,691
Advisory services	40,069	6,329	9,403	4,699	60,500	7,783	6,796	14,579	75,079
Merchandise	-	-	-	-	-	-	34,151	34,151	34,151
Postage and delivery	10,106	22,293	27,876	2,465	62,740	5,787	13,334	19,121	81,861
Website	460	2,534	2,534	-	5,528	-	2,315	2,315	7,843
Office	3,635	9,347	4,675	3,635	21,292	13,574	477	14,051	35,343
Insurance	2,406	7,912	11,751	2,252	24,321	4,352	7,696	12,048	36,369
Rent	12,544	12,544	12,544	12,544	50,176	12,544	12,544	25,088	75,264
Bank and credit card fees	-	-	153	-	153	4,343	50,897	55,240	55,393
Public relations	8,569	6,495	6,495	8,166	29,725	6,496	6,616	13,112	42,837
Miscellaneous	1,951	3,040	2,132	1,383	8,506	3,978	7,911	11,889	20,395
Telephone	1,629	1,629	1,629	1,619	6,506	1,639	1,749	3,388	9,894
Utilities	1,353	1,353	1,353	1,366	5,425	1,416	1,467	2,883	8,308
Miscellaneous patient services	-	57,572	15,091	-	72,663	-	4,491	4,491	77,154
Total non-personnel expenses	1,345,735	280,072	323,356	76,008	2,025,171	94,773	734,898	829,671	2,854,842
Total expenses before depreciation	1,505,639	374,997	544,415	119,409	2,544,460	182,696	1,097,117	1,279,813	3,824,273
Depreciation	1,963	11,183	1,963	1,963	17,072	1,964	1,962	3,926	20,998
Total expenses	\$ 1,507,602	\$ 386,180	\$ 546,378	\$ 121,372	\$ 2,561,532	\$ 184,660	\$ 1,099,079	\$ 1,283,739	\$ 3,845,271

See independent auditors' report.

**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
**SCHEDULE OF EXPENDITURES OF FEDERAL AWARDS**  
**YEAR ENDED JUNE 30, 2013**

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	<b>CFDA</b>			<b>Total</b>	
	<b>Number</b>	<b>Name of Grant</b>	<b>Grant Number</b>	<b>Expenditures</b>	<b>Grant Period</b>
Department of Health and Human Services - National Institute of Neurological Disorders and Stroke / National Center for Advancing Translational Sciences	93.853	Conference Grant	1R13NS0846-01	\$ 20,000	6/13/13 to 6/12/14

The accompanying schedule of expenditures of federal awards includes the federal grant activity of Families of Spinal Muscular Atrophy under programs of the federal government for the year ended June 30, 2013, and is presented on the accrual basis of accounting. Expenditures are recognized when they become a demand on current available financial resources. The information in this schedule is presented in accordance with the requirements of OMB Circular A-133, Audits of States, Local Governments, and Non-Profit Organizations. Therefore, some amounts presented in this schedule may differ from amounts presented in, or used in the preparation of, the general-purpose financial statements.

See independent auditors' report.

# INDEPENDENT AUDITORS' REPORT ON INTERNAL CONTROL OVER FINANCIAL REPORTING AND ON COMPLIANCE BASED ON AN AUDIT OF FINANCIAL STATEMENTS PERFORMED IN ACCORDANCE WITH GOVERNMENT AUDITING STANDARDS

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Families of Spinal Muscular Atrophy  
Elk Grove, Illinois

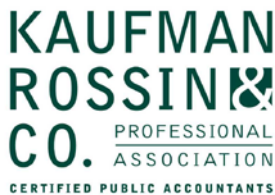
We have audited, in accordance with the auditing standards generally accepted in the United States of America and the standards applicable to financial audits contained in *Government Auditing Standards* issued by the Comptroller General of the United States, the financial statements of Families of Spinal Muscular Atrophy (the "Organization"), which comprise the statement of financial position as of June 30, 2013, and the related statements of activities, and cash flows for the year then ended, and the related notes to the financial statements, and have issued our report thereon dated October 21, 2013.

## Internal Control Over Financial Reporting

In planning and performing our audit of the financial statements, we considered Families of Spinal Muscular Atrophy's internal control over financial reporting (internal control) to determine the audit procedures that are appropriate in the circumstances for the purpose of expressing our opinion on the financial statements, but not for the purpose of expressing an opinion on the effectiveness of Families of Spinal Muscular Atrophy's internal control. Accordingly, we do not express an opinion on the effectiveness of the Organization's internal control.

*A deficiency in internal control* exists when the design or operation of a control does not allow management or employees, in the normal course of performing their assigned functions, to prevent, or detect and correct, misstatements on a timely basis. *A material weakness* is a deficiency, or a combination of deficiencies, in internal control, such that there is a reasonable possibility that a material misstatement of the entity's financial statements will not be prevented, or detected and corrected on a timely basis. *A significant deficiency* is a deficiency, or a combination of deficiencies, in internal control that is less severe than a material weakness, yet important enough to merit attention by those charged with governance.

Our consideration of internal control was for the limited purpose described in the first paragraph of this section and was not designed to identify all deficiencies in internal control that might be material weaknesses or significant deficiencies. Given these limitations, during our audit we did not identify any deficiencies in internal control that we consider to be material weaknesses. However, material weaknesses may exist that have not been identified.



### Compliance

As part of obtaining reasonable assurance about whether the Families of Spinal Muscular Atrophy's financial statements are free from material misstatement, we performed tests of its compliance with certain provisions of laws, regulations, contracts, and grant agreements, noncompliance with which could have a direct and material effect on the determination of financial statement amounts. However, providing an opinion on compliance with those provisions was not an objective of our audit, and accordingly, we do not express such an opinion. The results of our tests disclosed no instances of noncompliance that are required to be reported under *Government Auditing Standards*.

### Purpose of this Report

The purpose of this report is solely to describe the scope of our testing of internal control and compliance and the results of that testing, and not to provide an opinion on the effectiveness of the organization's internal control or on compliance. This report is an integral part of an audit performed in accordance with *Government Auditing Standards* in considering the organization's internal control and compliance. Accordingly, this communication is not suitable for any other purpose.

A handwritten signature in black ink that reads "Kaugman, Rossin & Co." The signature is written in a cursive style with a large, sweeping initial 'K'.

October 21, 2013  
Miami, Florida