



NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

**FINANCIAL STATEMENTS
DECEMBER 31, 2014**

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

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December 31, 2014

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Independent Auditor's Report

To the Board of Directors of
National Organization for Rare Disorders, Inc.:

Report on the Financial Statements

We have audited the accompanying financial statements of National Organization for Rare Disorders, Inc. (a New York corporation, not for profit) which comprise the statement of financial position as of December 31, 2014, and the related statements of activities, changes in net assets, cash flows and functional expenses for the year 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 audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. 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 National Organization for Rare Disorders, Inc. as of December 31, 2014, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Emphasis of Matter

As discussed in Note 9 to the financial statements, the 2013 financial statements have been restated. Our opinion is not modified with respect to this matter.

Alexander, Brown, Fenning & Co., P.C.
Boston, Massachusetts
May 20, 2015

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Financial Position
December 31, 2014

Assets	Unrestricted	Temporarily Restricted	Total
Current Assets:			
Cash	\$ 5,553,652	\$ 4,637,012	\$ 10,190,664
Certificates of deposit	1,451,712	-	1,451,712
Investments	272,502	-	272,502
Accounts receivable	633,444	200,000	833,444
Prepaid expenses	74,242	-	74,242
Total current assets	7,985,552	4,837,012	12,822,564
Property and Equipment, net	1,485,761	-	1,485,761
Software Under Development	967,628	-	967,628
Total assets	\$ 10,438,941	\$ 4,837,012	\$ 15,275,953
Liabilities and Net Assets			
Current Liabilities:			
Current portion of long-term debt	\$ 52,830	\$ -	\$ 52,830
Accounts payable	641,801	-	641,801
Accrued expenses	2,210,690	-	2,210,690
Research grants payable	955,096	-	955,096
Deferred revenue	771,811	-	771,811
Total current liabilities	4,632,228	-	4,632,228
Long-term Debt, net of current portion	543,382	-	543,382
Total liabilities	5,175,610	-	5,175,610
Net Assets:			
Unrestricted:			
Operating	3,406,154	-	3,406,154
Property, equipment and software under development	1,857,177	-	1,857,177
Total unrestricted	5,263,331	-	5,263,331
Temporarily restricted	-	4,837,012	4,837,012
Total net assets	5,263,331	4,837,012	10,100,343
Total liabilities and net assets	\$ 10,438,941	\$ 4,837,012	\$ 15,275,953

The accompanying notes are an integral part of these statements.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Activities

For the Year Ended December 31, 2014

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Operating Revenues and Support:			
Program grants	\$ 2,972,154	\$ 19,371,580	\$ 22,343,734
Patient assistance and research program fees	2,243,559	-	2,243,559
Membership dues	1,257,819	-	1,257,819
Special events revenue	951,074	-	951,074
Contributions and bequests	741,884	-	741,884
Royalties and other	191,748	-	191,748
Federated grants	41,540	-	41,540
Investment income	20,445	-	20,445
Net assets released from purpose restrictions	15,878,540	(15,878,540)	-
	<u>24,298,763</u>	<u>3,493,040</u>	<u>27,791,803</u>
Operating Expenses:			
Program services:			
Patient services	17,625,423	-	17,625,423
Advocacy	406,798	-	406,798
Research and medical & scientific affairs	736,109	-	736,109
Membership and education	1,058,262	-	1,058,262
	<u>19,826,592</u>	<u>-</u>	<u>19,826,592</u>
Support services:			
General and administrative	2,109,853	-	2,109,853
Development and communications	1,515,212	-	1,515,212
	<u>3,625,065</u>	<u>-</u>	<u>3,625,065</u>
	<u>23,451,657</u>	<u>-</u>	<u>23,451,657</u>
Changes in net assets from operations	847,106	3,493,040	4,340,146
Net Loss on Investments	<u>(8,305)</u>	<u>-</u>	<u>(8,305)</u>
Changes in net assets	<u>\$ 838,801</u>	<u>\$ 3,493,040</u>	<u>\$ 4,331,841</u>

The accompanying notes are an integral part of these statements.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Changes in Net Assets
For the Year Ended December 31, 2014

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Net Assets, December 31, 2013, as previously stated	\$ 4,409,025	\$ 1,923,628	\$ 6,332,653
Prior period adjustment	<u>15,505</u>	<u>(579,656)</u>	<u>(564,151)</u>
Net Assets, December 31, 2013, as restated	4,424,530	1,343,972	5,768,502
Changes in net assets	<u>838,801</u>	<u>3,493,040</u>	<u>4,331,841</u>
Net Assets, December 31, 2014	<u><u>\$ 5,263,331</u></u>	<u><u>\$ 4,837,012</u></u>	<u><u>\$ 10,100,343</u></u>

The accompanying notes are an integral part of these statements.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Cash Flows

For the Year Ended December 31, 2014

Cash Flows from Operating Activities:

Changes in net assets	\$ 4,331,841
Adjustments to reconcile changes in net assets to net cash provided by operating activities:	
Depreciation	181,773
Donated investments	(5,941)
Net loss on investments	8,305
Changes in operating assets and liabilities:	
Accounts receivable	(232,667)
Prepaid expenses	30,593
Accounts payable	354,642
Accrued expenses	327,453
Research grants payable	123,718
Deferred revenue	<u>(128,882)</u>
Net cash provided by operating activities	<u>4,990,835</u>

Cash Flows from Investing Activities:

Reinvested interest earned on certificates of deposit	(4,873)
Proceeds from sales of investments	1,037
Investment in software under development	(199,411)
Acquisition of property and equipment	<u>(20,236)</u>
Net cash used in investing activities	<u>(223,483)</u>

Cash Flows from Financing Activities

Principal payments on long-term debt	<u>(50,310)</u>
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Net Change in Cash 4,717,042

Cash:

Beginning of year 5,473,622

End of year \$ 10,190,664

Supplemental Disclosure of Cash Flow Information:

Cash paid for interest \$ 30,559

Supplemental Disclosure of Non-Cash Transactions:

Donated investments \$ 5,941

The accompanying notes are an integral part of these statements.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statement of Functional Expenses
For the Year Ended December 31, 2014

	Program Services				Support Services				Total
	Patient Services	Advocacy	Research and Medical & Scientific Affairs	Membership and Education	Total Program Services	General and Administrative	Development and Communications	Total Support Services	
Program Grants	\$ 16,735,230	\$ -	\$ 417,000	\$ -	\$ 17,152,230	\$ -	\$ -	\$ -	\$ 17,152,230
Personnel and Related:									
Salaries	508,768	156,711	182,919	271,251	1,119,649	1,220,230	473,726	1,693,956	2,813,605
Payroll taxes and fringe benefits	144,231	40,752	26,415	39,384	250,782	262,696	109,432	372,128	622,910
Employee related costs	128	6	6	70	210	8,116	828	8,944	9,154
Total personnel and related	653,127	197,469	209,340	310,705	1,370,641	1,491,042	583,986	2,075,028	3,445,669
Occupancy:									
Rent	-	55,906	9,492	-	65,398	109,853	38,809	148,662	214,060
Utilities, equipment and storage	26,168	5,404	4,968	11,861	48,401	40,436	14,822	55,258	103,659
Repairs and maintenance	14,725	-	2,762	4,269	21,756	13,879	6,291	20,170	41,926
Interest	11,027	-	1,929	3,351	16,307	9,865	4,388	14,253	30,560
Property insurance	8,975	1,493	1,887	2,923	15,278	11,154	3,871	15,025	30,303
Total occupancy	60,895	62,803	21,038	22,404	167,140	185,187	68,181	253,368	420,508
Other:									
Travel and meeting	17,077	10,276	8,728	495,948	532,029	88,588	90,949	179,537	711,566
Marketing	11,102	9,468	16	164,959	185,545	4,137	386,978	391,115	576,660
Professional fees	16,245	95,226	59,842	3,985	175,298	90,775	38,340	129,115	304,413
Special events	-	-	-	-	-	-	223,905	223,905	223,905
Data systems	21,654	9,871	3,637	8,572	43,734	104,812	32,809	137,621	181,355
Office supplies	53,000	2,573	2,701	29,008	87,282	19,594	23,532	43,126	130,408
Dues, subscriptions and registrations	514	10,877	504	438	12,333	18,607	18,122	36,729	49,062
Miscellaneous	558	203	364	702	1,827	29,857	1,433	31,290	33,117
Conferences and patient travel	-	206	430	6,577	7,213	375	17,868	18,243	25,456
Insurance	4,583	776	996	1,489	7,844	5,830	1,861	7,691	15,535
Total other	124,733	139,476	77,218	711,678	1,053,105	362,575	835,797	1,198,372	2,251,477
Total operating expenses before depreciation	17,573,985	399,748	724,596	1,044,787	19,743,116	2,038,804	1,487,964	3,526,768	23,269,884
Depreciation	51,438	7,050	11,513	13,475	83,476	71,049	27,248	98,297	181,773
Total operating expenses	\$ 17,625,423	\$ 406,798	\$ 736,109	\$ 1,058,262	\$ 19,826,592	\$ 2,109,853	\$ 1,515,212	\$ 3,625,065	\$ 23,451,657

The accompanying notes are an integral part of these statements.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2014

1. OPERATIONS AND NONPROFIT STATUS

National Organization for Rare Disorders, Inc. (NORD) is a not-for-profit organization incorporated on May 4, 1983, under the laws of the State of New York.

NORD was formed to provide information on rare disorders and related resources, to aid government agencies in activities pursuant to the Orphan Drug Act, to encourage and promote increased scientific and clinical research on rare disorders, to support and mentor disease-specific patient organizations, and to provide services to patients and their families, especially to enhance their access to medical treatment for their diseases. NORD manages both indigent care drug programs that provide medication at no cost to those in need and financial hardship relief programs to provide individuals who meet objective criteria with insurance premium and co-payment assistance through funds provided by various pharmaceutical companies.

NORD's main office is in Danbury, Connecticut, with additional offices in Massachusetts and Washington, D.C.

NORD is exempt from Federal income taxes as an organization (not a private foundation) formed for charitable purposes under Section 501(c)(3) of the Internal Revenue Code (IRC). NORD is also exempt from state income taxes. Donors may deduct contributions made to NORD within the requirements of the IRC.

2. SIGNIFICANT ACCOUNTING POLICIES

NORD's financial statements have been prepared in accordance with accounting standards generally accepted in the United States of America (U.S. GAAP). References to U.S. GAAP in these notes are to the FASB Accounting Standards Codification (ASC).

Certificates of Deposit

The certificates of deposit at December 31, 2014, mature at various dates through December 2015 and earn interest at rates ranging from .15% to .30%. All certificates of deposit are shown as current in the accompanying statement of financial position.

Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2014, consist mainly of amounts due for program services. An allowance for doubtful accounts is based on collection experience and other circumstances which may affect the ability of NORD to collect. No allowance was deemed necessary at December 31, 2014.

Investments

The primary investment objective is to earn a total rate of return modestly greater than provided by general savings accounts and protecting assets while earning a return. Investment allocations are reviewed by NORD on a semi-annual basis and adjustments are made when necessary.

Fair Value Measurements

NORD follows the accounting and disclosure standards pertaining to ASC Topic, *Fair Value Measurements*, for qualifying assets and liabilities. Fair value is defined as the price that NORD would receive upon selling an asset or pay to settle a liability in an orderly transaction between market participants.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2014

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Fair Value Measurements (Continued)

NORD uses a framework for measuring fair value that includes a hierarchy that categorizes and prioritizes the sources used to measure and disclose fair value. This hierarchy is broken down into three levels based on inputs that market participants would use in valuing the financial instruments based on market data obtained from sources independent of NORD. Inputs refer broadly to the assumptions that market participants would use in pricing the financial instrument, including assumptions about risk. Inputs may be observable or unobservable. Observable inputs are inputs that reflect the assumptions market participants would use in pricing the financial instrument developed based on market data obtained from sources independent of the reporting entity. Unobservable inputs are inputs that reflect the reporting entity's own assumptions about the assumptions market participants would use in pricing the asset developed based on the best information available. The three-tier hierarchy of inputs is summarized in the three broad levels as follows:

Level 1 - Inputs that reflect unadjusted quoted prices in active markets for identical assets at the measurement date.

Level 2 - Inputs other than quoted prices that are observable for the asset either directly or indirectly, including inputs in markets that are not considered to be active.

Level 3 - Inputs that are unobservable and which require significant judgment or estimation.

An asset or liability's level within the framework is based upon the lowest level of any input that is significant to the fair value measurement. All qualifying assets and liabilities are valued using Level 1 inputs.

Property and Equipment and Depreciation

Property and equipment (see Note 4) are recorded at cost when purchased or at fair value at the time of donation. Renewals and betterments are capitalized, while repairs and maintenance are expensed as they are incurred.

Depreciation is computed using the straight-line method over the following estimated useful lives:

	<u>Estimated Useful Lives</u>
Building and improvements	20 - 40 years
Furniture and fixtures	5 - 10 years
Computers and computer software	5 years
Leasehold improvements	Term of lease

Software Under Development

Software under development includes the cost of developing a system to track and monitor patient expenses, an internal use website, and a registry of rare diseases. The cost related to software or modules not placed in service as of December 31, 2014, was \$967,628 and is reflected as software under development in the accompanying statement of financial position.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2014

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Research Grants Payable

Research grants are recorded when awarded by NORD. Payments are made when research is considered substantially complete. Research grants expected to be paid during the subsequent fiscal year are shown as current liabilities in the accompanying statement of financial position.

Deferred Revenue

Deferred revenue consists of membership revenue received in advance of the membership effective date and contract advances which will be recognized as revenue when the services are provided.

Net Assets

Unrestricted Net Assets

Unrestricted net assets are those net resources that bear no external restrictions and are generally available for use by NORD. NORD has grouped its unrestricted net assets into the following categories:

Operating - Represents resources available to carry on the operations of NORD.

Property, equipment and software under development - Represent the activities relating to NORD's property, equipment and software under development, net of related debt.

Temporarily Restricted Net Assets

Temporarily restricted net assets represent amounts received or committed with donor restrictions which have not yet been expended for their designated purpose (purpose restricted) or amounts for use in future periods (time restricted). As of December 31, 2014, all amounts included in temporarily restricted net assets were purpose restricted.

Revenue Recognition

NORD reports gifts and grants of cash and other assets as temporarily restricted revenue and net assets, if they are received or unconditionally committed with donor stipulations that limit the use of the asset. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions. Revenue from unrestricted grants and contributions is recorded when received or committed.

Patient assistance and research program fees revenue is recorded as services are provided and revenue is earned. Royalty income is recorded annually in accordance with a contract agreement from publication of certain curricula and software developed by NORD. Special events revenue is recognized in the year the event occurs. Membership dues revenue is recorded when earned at the beginning of the year the membership is effective. All other revenue is recorded when earned.

NORD is and may be named beneficiary of trusts and wills. The amounts to be received, if any, cannot always be determined and are therefore not reflected in the accompanying financial statements until received. NORD received a bequest of \$12,312 for the year ended December 31, 2014, which is included in contributions and bequests in the accompanying statement of activities. Subsequent to year-end, NORD was the named beneficiary in a will.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2014

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred.

Expense Allocation

Expenses related directly to a program are allocated to that program, while other expenses are allocated based upon management's estimate of the percentage attributable to each program.

Estimates

The preparation of financial statements in accordance with U.S. GAAP requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

Income Taxes

NORD accounts for uncertainty in income taxes in accordance with ASC Topic, *Income Taxes*. This standard clarifies the accounting for uncertainty in tax positions and prescribes a recognition threshold and measurement attribute for the financial statements regarding a tax position taken or expected to be taken in a tax return. NORD has determined that there are no uncertain tax positions which qualify for either recognition or disclosure in the financial statements at December 31, 2014. NORD's information returns are subject to examination by the Federal and state jurisdictions and generally remain open for the most recent three years.

Subsequent Events

Subsequent events have been evaluated through May 20, 2015, which is the date the financial statements were available to be issued. There were no events that met the criteria for recognition or disclosure in the financial statements, except as noted in the revenue recognition footnote on page 9.

3. INVESTMENTS

Investments are presented in the accompanying financial statements at fair value using Level 1 inputs (see Note 2) and are comprised of fixed income mutual funds and donated stock as of December 31, 2014.

Investments are not insured and are subject to ongoing market fluctuations. Investments have been classified as short-term in the accompanying statement of financial position based upon management's intent.

NORD received donated stock with a market value of \$5,941 for the year ended December 31, 2014. It is NORD's policy to sell donated stock within a three month period to maximize the donation. As of December 31, 2014, approximately \$5,408 of donated stock remained in the investment balance.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2014

3. INVESTMENTS (Continued)

Net loss on investments consists of the following as of December 31, 2014:

Realized loss on investments	\$ (3)
Unrealized loss on investments	<u>(8,302)</u>
Net loss on investments	<u>\$ (8,305)</u>

4. PROPERTY AND EQUIPMENT

Net property and equipment consist of the following as of December 31, 2014:

Land	\$ 505,203
Building and improvements	767,812
Furniture and fixtures	1,314,099
Computers and computer software	334,735
Leasehold improvements	<u>11,910</u>
	2,933,759
Less - accumulated depreciation	<u>1,447,998</u>
Net property and equipment	<u>\$ 1,485,761</u>

5. LONG-TERM DEBT

NORD has a mortgage note payable to a bank which is secured by property owned by NORD. Payments of principal and interest at 4.9% are due in monthly installments of \$6,739 through February 2024. The balance outstanding on the note was \$596,212 as of December 31, 2014.

The note agreement contains various covenants with which NORD must comply. At December 31, 2014, NORD was in compliance with the covenants.

The future principal payments over the next five fiscal years are as follows:

2015	\$ 52,830
2016	\$ 55,478
2017	\$ 58,258
2018	\$ 61,178
2019	\$ 64,244

6. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in January 2018 and April 2019, respectively. The terms of these lease agreements are five years and rents increase annually under both leases. The facility leases require NORD to maintain certain insurance coverage and pay for its proportionate share of real estate taxes and operating expenses, as defined in the agreement. Rent expense was \$214,060 for the year ended December 31, 2014, and is reflected as rent in the accompanying statement of functional expenses.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2014

6. LEASE AGREEMENTS (Continued)

Future minimum lease payments under these agreements are as follows:

2015	\$ 220,716
2016	\$ 224,388
2017	\$ 227,448
2018	\$ 147,928
2019	\$ 83,820

Both lease agreements contain renewal options, which have not been exercised.

7. EMPLOYMENT BENEFIT PLANS

NORD has adopted a tax-deferred pension plan under Section 403(b) of the IRC for all employees. NORD contributes 5% of each participant's annual salary to the plan. NORD's contributions for the year ended December 31, 2014, totaled \$101,686, which is included in payroll taxes and fringe benefits in the accompanying statement of functional expenses.

8. CONCENTRATIONS

NORD maintains its operating cash balances in various banks. The Federal Deposit Insurance Corporation (FDIC) insures balances at each bank up to certain amounts. At certain times during the year ended December 31, 2014, cash balances exceeded the insured amounts. NORD has not experienced any losses in such accounts. NORD believes it is not exposed to any significant credit risk on its operating cash balance.

Revenue and accounts receivable concentrations are comprised of the following private donors at December 31, 2014:

<u>Payor</u>	<u>Percentage of Accounts Receivable</u>	<u>Percentage of Operating Revenue and Support</u>
A	26%	3%
B	23%	- %
C	16%	13%
D	- %	19%

9. PRIOR PERIOD ADJUSTMENTS

During fiscal year 2014, NORD discovered certain deferred revenue balances were improperly recorded as temporarily restricted net assets. The effect of this misclassification caused a \$331,624 understatement of deferred revenue and a \$248,032 overstatement of accounts receivable, resulting in a \$579,656 overstatement of temporarily restricted net assets.

During fiscal year 2014, NORD also discovered that salary, payroll taxes and fringe benefits related to software under development were improperly expensed for the year ended December 31, 2013. The effect of this misclassification caused a \$15,505 overstatement of expenses and understatement of software under development, resulting in a \$15,505 understatement of unrestricted net assets.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.Notes to Financial Statements
December 31, 2014

9. PRIOR PERIOD ADJUSTMENTS (Continued)

The net effect of these misclassifications resulted in a misstatement of \$564,151 to total net assets as of December 31, 2013.

Net assets as of December 31, 2013, have been restated as follows:

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Net assets, December 31, 2012, as previously stated	\$ 4,916,677	\$ 2,182,446	\$ 7,099,123
Changes in net assets	<u>(507,652)</u>	<u>(258,818)</u>	<u>(766,470)</u>
Net assets, December 31, 2013, as previously stated	4,409,025	1,923,628	6,332,653
Prior period adjustment	<u>15,505</u>	<u>(579,656)</u>	<u>(564,151)</u>
Net assets, December 31, 2013, as restated	<u>\$ 4,424,530</u>	<u>\$ 1,343,972</u>	<u>\$ 5,768,502</u>