

**INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH**  
**FINANCIAL STATEMENTS AND SUPPLEMENTARY INFORMATION**  
**FOR THE TWELVE MONTHS ENDED DECEMBER 31, 2017**  
**WITH COMPARATIVE TOTALS FOR 2016**



## TABLE OF CONTENTS

	Page No.
REPORT OF INDEPENDENT AUDITORS	2
FINANCIAL STATEMENTS	
Statement of Financial Position	4
Statement of Activities	5
Statement of Functional Expenses	6
Statement of Cash Flows	7
Notes to Financial Statements	8

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## INDEPENDENT AUDITOR'S REPORT

To the Board of Directors of  
International Foundation For CDKL5 Research  
Houston, Texas

I have audited the accompanying financial statements of International Foundation For CDKL5 Research (a nonprofit organization), which comprise the statement of financial position as of December 31, 2017, and the related statements of activities, functional expenses, and cash flows 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**

My responsibility is to express an opinion on these financial statements based on my audit. I conducted my audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that I 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, I 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.

I believe that the audit evidence I have obtained is sufficient and appropriate to provide a basis for my audit opinion.

### **Opinion**

In my opinion, the financial statements referred to above present fairly, in all material respects, the financial position of International Foundation For CDKL5 Research as of December 31, 2017, 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.

### **Report on Summarized Comparative Information**

I have previously audited International Foundation For CDKL5 Research's 2016 financial statements, and I expressed an unmodified audit opinion on those audited financial statements in my report dated June 30, 2017. In my opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2016, is consistent, in all material respects, with the audited financial statements from which it has been derived.

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Judy L. Arfa, C. P. A.  
Houston, Texas  
October 8, 2018

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

STATEMENT OF FINANCIAL POSITION

DECEMBER 31, 2017  
WITH COMPARATIVE TOTALS FOR 2016

	<u>2017</u>	<u>2016</u>
<b>Assets</b>		
Cash and cash equivalents	\$ 734,887	\$ 708,157
Accounts Receivable	8,523	1,000
Investments - short-term	170,451	97,389
<b>Total assets</b>	<u>\$ 913,861</u>	<u>\$ 806,546</u>
<b>Liabilities and Net Assets</b>		
<b>Liabilities:</b>		
Accounts payable	\$ 4,924	\$ 0
Due to research foundations	25,000	20,000
<b>Total Liabilities</b>	<u>29,924</u>	<u>20,000</u>
<b>Net Assets:</b>		
Unrestricted	883,937	786,546
<b>Total Net Assets</b>	<u>883,937</u>	<u>786,546</u>
<b>Total Liabilities and Net Assets</b>	<u>\$ 913,861</u>	<u>\$ 806,546</u>

See accompanying notes to financial statements.



## INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

## STATEMENT OF ACTIVITIES

YEAR ENDED DECEMBER 31, 2017 WITH COMPARATIVE TOTALS FOR 2016

	Unrestricted	Temporarily Restricted	Totals 2017	Totals 2016
<b>Revenue, Gains, and Other Support</b>				
Merchandise sales	\$ 3,046	\$	\$ 3,046	\$ 7,054
Cost of goods sold	(680)		(680)	(965)
<b>Net</b>	<u>2,366</u>		<u>2,366</u>	<u>6,089</u>
Contributions	204,544		204,544	278,075
Contributions in-kind	309,870		309,870	332,337
Family conference income				16,858
Special events	141,012		141,012	149,924
Membership fees				369
Investment revenue	34,702		34,702	7,500
<b>Total Revenue, Gains, and Other Support</b>	<u>692,494</u>		<u>692,494</u>	<u>791,152</u>
<b>Expenses</b>				
Program service expenses	316,362		316,362	364,212
Research grants	214,875		214,875	661,856
Supporting services	6,689		6,689	5,819
Fundraising	56,177	0	56,177	53,397
<b>Total Expenses</b>	<u>594,103</u>		<u>594,103</u>	<u>1,085,284</u>
<b>Increase (decrease) in net assets</b>	<u>98,391</u>		<u>98,391</u>	<u>(294,132)</u>
<b>Net assets, beginning of year</b>	<u>785,546</u>		<u>785,546</u>	<u>1,080,678</u>
<b>Net assets, end of year</b>	<u>\$ 883,937</u>	<u>\$ 0</u>	<u>\$ 883,937</u>	<u>\$ 786,546</u>

See accompanying notes to financial statements.

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH  
STATEMENT OF FUNCTIONAL EXPENSES  
YEAR ENDED DECEMBER 31, 2017  
WITH COMPARATIVE TOTALS FOR 2016

	Program Service Expenses	Research Grants	Supporting Services	Fundraising	2017 Totals	2016 Totals
<b>Expenses</b>						
Postage	2,642				2,642	2,858
Printing	274				274	813
Supplies	1,353				1,353	1,140
Conferences	8,321				8,321	37,474
Insurance	1,464		298	720	2,482	2,481
Value-volunteer hours*	285,000				285,000	307,000
Research grants		214,875			214,875	661,856
Business expenses	392				392	123
Business registration			70		70	90
Professional fees	4,030				4,030	5,900
In-kind expenses ***				24,870	24,870	25,336
Bank charges			5,032		5,032	4,174
Telephone	928		155	464	1,547	3,716
Family support	136				136	153
Memberships & dues						200
Gifts-Volunteers	1,301				1,301	327
Event expenses				23,601	23,601	22,262
Donor management	6,521		1,134	6,522	14,177	8,612
Storage-Samples	4,000				4,000	0
Operations						769
<b>Total Expenses</b>	<b>316,362</b>	<b>214,875</b>	<b>6,689</b>	<b>56,177</b>	<b>594,103</b>	<b>1,085,284</b>

\* See page 12, Note 4

\*\*\* Fundraising events

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

STATEMENTS OF CASH FLOWS

YEAR ENDED DECEMBER 31, 2017 WITH COMPARATIVE TOTALS FOR 2016

	2017	2016
<b>Cash Flows From Operating Activities</b>		
Increase (decrease) in net assets	\$ 98,391	\$ (294,132)
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:		
Interest income on investments	(1,958)	(1,287)
Unrealized (gain) loss on investments	(31,823)	(4,805)
(Increase) Decrease in accounts receivable	(8,523)	(1,000)
Increase (Decrease) in accounts payable	4,924	
Increase (Decrease) in amounts due to research foundations	5,000	20,000
<b>Net Cash Provided (Used) by Operating Activities</b>	<u>66,011</u>	<u>(281,224)</u>
<b>Cash Flows From Investing Activities</b>		
Purchase of investments	(39,281)	(14,014)
<b>Net Cash Provided (Used) by Investing Activities</b>	<u>(39,281)</u>	<u>(14,014)</u>
 <b>Net Change in Cash and Cash Equivalents</b>	 26,730	 (295,238)
 <b>Cash and cash equivalents, beginning of year</b>	 708,157	 1,003,395
<b>Cash and cash equivalents, end of year</b>	<u>\$ 734,887</u>	<u>\$ 708,157</u>
 <b>Cash and cash equivalents, unrestricted</b>	 \$ 734,887	 \$ 708,157
<b>Total cash and cash equivalents</b>	<u>\$ 734,887</u>	<u>\$ 708,157</u>

See accompanying notes to financial statements.



# INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

## NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 AND DECEMBER 31, 2016

### NOTE 1 - ORGANIZATION

International Foundation For CDKL5 Research (the Organization) is a not-for-profit organization incorporated in the State of Ohio in 2009 and is exempt from federal income taxes pursuant to Section 501(c)(3) of the Internal Revenue Code. The Organization is governed by a seven-member Board of Directors. The Board of Directors is selected pursuant to the bylaws of the Organization, and they significantly influence operations. The Board of Directors has the primary accountability for the fiscal affairs of the Organization.

CDKL5 is a rare X-linked genetic disorder that results in difficult to control seizures. Most of the children cannot walk, talk, or feed themselves. Many children suffer with vision and gastrointestinal problems.

CDKL5 stands for cyclin-dependent kinase-like 5, and is located on the X chromosome. The CDKL5 gene provides instructions for making a protein that is essential for normal brain development. Although little is known about the protein's function, it may play a role in regulating the activity of other genes, including the MECP2 gene (of Rett Syndrome). The CDKL5 protein acts as a kinase, which is an enzyme that changes the activity of other proteins by adding oxygen and phosphate atoms (a phosphate group) at specific positions. Researchers have not yet determined which proteins are targeted by the CDKL5 protein.

The International Foundation for CDKL5 Research (IFCR) was formed by a group of dedicated parents of CDKL5 children, who dared to dream of something life changing for their children - a cure. The Organization raises funds that are being used to fund research that will lead to a cure for this very debilitating disease. IFCR is committed to collaborating with leading scientists and researchers from around the world who are dedicated to finding a cure for CDKL5.

The Organization has many goals including aggressive research, studies to improve the quality of life for children who have been diagnosed with CDKL5, and a testing of compounds to identify possible neurologic modifiers.

The Organization is supported primarily by individuals, corporations, and philanthropic organizations. Its greatest strength is the dedication of its grassroots leaders and volunteers.

# INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

## NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 AND DECEMBER 31, 2016

### NOTE 2 – SIGNIFICANT ACCOUNTING POLICIES

The financial statements of International Foundation For CDKL5 Research have been prepared on the accrual basis.

Significant accounting policies are summarized below:

Contributions and Net Asset Classification – Contributions and the related net assets are classified based on the existence or absence of donor-imposed restrictions, as follows:

Unrestricted net assets include those net assets whose use is not restricted by donor-imposed stipulations even though their use may be limited in other respects such as by contract or board designation.

Temporarily restricted net assets include contributions restricted by the donor for specific purposes or time periods. When a purpose restriction is accomplished or a time restriction ends, temporarily restricted net assets are released to unrestricted net assets.

Permanently restricted net assets include contributions that donors have restricted in perpetuity. The income from such gifts may be used to support the specified purpose.

Revenues are reported as increases in unrestricted net assets, and expenses are reported as decreases in unrestricted net assets. Amounts are transferred from temporarily restricted net assets to unrestricted net assets as soon as the donor imposed restrictions are removed.

Cash and Cash Equivalents – For purposes of the statement of cash flows, International Foundation For CDKL5 Research considers all highly liquid investments available for current use with an initial maturity of three months or less to be cash equivalents. Cash is held in an interest bearing demand account at one financial institution. The account at this institution is insured by the Federal Deposit Insurance Corporation.

Pledges Receivable – Pledges receivable that are expected to be collected within one year are recorded at net realizable value. Amounts expected to be collected in more than one year are discounted to estimate the present value of future cash flows. Program cost reimbursements due from grantors are included in this amount, should there be any reimbursements due to the Organization at the end of the fiscal year.



# INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

## NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 AND DECEMBER 31, 2016

### NOTE 2 – SIGNIFICANT ACCOUNTING POLICIES (CONT.)

Investments - Investments in marketable securities with readily determinable fair values and all investments in debt securities are reported at their fair values on the statement of financial position. Unrealized gains and losses are included in the change in net assets.

Property and Equipment - Property and equipment purchased by International Foundation For CDKL5 Research are recorded at cost. Donations of property and equipment are recorded at their fair value at the date of the gift. All purchases and donations in excess of \$1,000 are capitalized. Depreciation is provided on the straight-line method based upon estimated useful lives of 25 – 40 years for buildings and leasehold improvements and 5 – 7 years for equipment, vehicles, and furniture. Gains or losses on retired or sold property and equipment are reflected in income for the period. The proceeds from such sales which are not legally required or expected to be reinvested in property and equipment are transferred to unrestricted net assets.

Public Support and Revenue - Financial ASC 958-605-25-2 and 958-605-30-2 (formerly SFAS No. 116) generally requires measuring contributions received at the fair value of the assets or services received or promised, or the fair value of the liabilities satisfied. Contributions are recognized as revenues or gains in the period they are received, even if the donor has restricted their use and the restriction will be met in a future reporting period; that is, none are deferred. As a result, contributions are recorded immediately either as an increase in unrestricted net assets, temporarily restricted net assets, or permanently restricted net assets, depending on the nature of the donor restrictions, if any.

Restricted Support - After determining that support should be recorded in the financial statements, the organization must determine whether the donor has restricted its use in some manner or to some time period. For example, a donor may specify that a gift be used for the operation of a particular program, the acquisition of property or equipment, or an endowment, whereby only income generated by the gift may be used for operating purposes. Restrictions may be explicit (such as a letter specifying that the contribution be used for a specific research program) or implicit (such as gifts received in a capital improvements drive or in an appeal for a particular program).

Temporary and Permanent Restrictions - Generally, a restriction is temporary if the organization is authorized to deplete what was donated, such as contributions restricted to purchase assets or to fund program costs; otherwise, it is permanent. Permanent restrictions are those that permanently restrict the organization's use of contributed assets (such as an endowment under which the principal must remain intact). Sometimes an endowment instrument temporarily restricts the use of the income from the principal, such as an endowment to a school requiring the income to be used to fund the compensation of a special needs instructor. Another example of a permanent restriction is land donated for the organization's permanent use.

# INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

## NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 AND DECEMBER 31, 2016

### NOTE 2 – SIGNIFICANT ACCOUNTING POLICIES (CONT.)

A temporarily restricted contribution generally is recognized when received and is reclassified from temporarily restricted net assets to unrestricted net assets when the donor's restriction is satisfied or when the stipulated time has elapsed. Cash received to support the activities of a particular program would be reported as contribution revenue, increasing temporarily restricted net assets. When expenditures for the program are incurred, the financial statements would report a reduction in temporarily restricted net assets and an increase in unrestricted net assets.

Unrestricted support contributions not restricted by time or manner of use are recognized as unrestricted support in the period in which they are received (or the promise is made). However, if a donor has stipulated that funds are to be used in a subsequent period, the contribution is considered restricted. Unconditional promises to give contributions to be received in future periods are assumed to be temporarily restricted unless the donor explicitly states that the contribution is to support the current period.

Contributions Whose Restrictions Are Met in the Same Year - Restricted contributions may be reported as unrestricted support if (a) the restrictions are met in the same reporting period, (b) that policy is followed consistently, (c) the policy is disclosed, and (d) the organization has a similar policy for accounting for restricted investment income and gains. For example, an organization may receive a \$50,000 contribution to fund the cost of a one-week educational seminar. If the \$50,000 is received in the same year the seminar is held, the donation can be reflected as an unrestricted contribution in the statement of activities provided the organization meets the criteria in this paragraph. If the educational seminar straddled the organization's year end and restrictions on only \$25,000 of the donation were met, the statement of activities could reflect unrestricted contributions of \$25,000 and temporarily restricted contributions of \$25,000.

Designations Imposed Internally - Sometimes, the Board of directors may designate a portion of unrestricted net assets for a specific purpose as a management planning tool. For example, the board of directors may designate a certain amount of current year contributions to be used to fund the purchase of new software. Those board designations are not restrictions because the designations may be reversed by the board, and they do not alter the nature of unrestricted contributions.



INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 AND DECEMBER 31, 2016

NOTE 2 – SIGNIFICANT ACCOUNTING POLICIES (CONT.)

Federal Income Taxes – International Foundation For CDKL5 Research is exempt from federal income tax under Internal Revenue Code Section 501©(3) and is classified as a public charity under 509(a)(1) and 170(b)(1)(A)(i).

Estimates – 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 certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

NOTE 3 – CASH AND CASH EQUIVALENTS

Cash and cash equivalents as of December 31, 2017 and December 31, 2016 consisted of the following:

	<u>2017</u>		<u>2016</u>	
	<u>Cost</u>	<u>Fair Value</u>	<u>Cost</u>	<u>Fair Value</u>
Checking	\$ 314,759	\$ 314,759	\$ 255,796	\$ 255,796
Money market funds	<u>420,128</u>	<u>420,128</u>	<u>452,361</u>	<u>452,361</u>
Total	<u>\$ 734,887</u>	<u>734,887</u>	<u>\$ 708,157</u>	<u>\$ 708,157</u>

NOTE 4 – DONATED SERVICES

Contributions of services are recognized when services received (a) create or enhance non-financial assets or (b) require specialized skills and are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation. A substantial number of volunteers have contributed significant amounts of time in connection with programs, administration, and fundraising for which an amount has been recorded in the financial statements, because the services did meet the criteria for recognition under generally accepted accounting principles. The estimated value of these volunteer services is \$285,000 for the year ending December 31, 2017 and \$307,000 for the year ending December 31, 2016. This amount is reflected in the financial statements.



# INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

## NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017 AND DECEMBER 31, 2016

### NOTE 5 – IN-KIND DONATIONS

Noncash gifts, including donated food, auction items, supplies, and equipment, are reported on the financial statements. They are recorded based on their fair market value on the date of the gift. The estimated fair market value of donated food, auction items, supplies, and equipment for the years ended December 31, 2017 and December 31, 2016 is \$24,870 and \$25,337, respectively.

### NOTE 6 – INVESTMENTS

The fair value measurements and levels within the fair value hierarchy of those measurements for the assets reported at fair value on a recurring basis at December 31, 2017 and December 31, 2016 consisted of the following:

	<u>2017</u>		<u>2016</u>	
	Significant Observable Inputs		Significant Observable Inputs	
	<u>Fair Value</u>	<u>Level 2</u>	<u>Fair Value</u>	<u>Level 2</u>
Equities	\$ 170,451	\$ 170,451	\$97,389	\$97,389
Total	<u>\$ 170,451</u>	<u>\$ 170,451</u>	<u>\$97,389</u>	<u>\$97,389</u>

Return on investment is as follows for the years ending December 31, 2017 and December 31, 2016.

	<u>2017</u>	<u>2016</u>
Interest/Dividend Income	\$ 1,958	\$ 1,287
Contributions of Securities	39,281	14,014
Unrealized gains (losses)	<u>31,823</u>	<u>4,805</u>
Total	<u>\$ 73,062</u>	<u>\$ 20,106</u>

### NOTE 7 – AMOUNTS DUE TO RESEARCH FOUNDATIONS

Amounts due to research foundations at December 31, 2017 and December 31, 2016 consist of the following:

	<u>2017</u>	<u>2016</u>
Due in less than one year	\$ 25,000	\$ 20,000
Total amounts due	<u>\$ 25,000</u>	<u>\$ 20,000</u>

**INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH**

**NOTES TO FINANCIAL STATEMENTS**

**DECEMBER 31, 2017 AND DECEMBER 31, 2016**

**NOTE 8 – PRIOR YEARS SUMMARIZED DATA**

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in accordance with generally accepted accounting principles. Accordingly, such information should be read in conjunction with the organization's financial statements for the year ended December 31, 2016, from which the summarized information was derived.

**NOTE 9 – CONCENTRATION OF CREDIT RISK**

Financial instruments which potentially subject the Organization to credit risk include bank deposits. The accounts at this institution are insured by the Federal Deposit Insurance Corporation up to \$250,000. The bank accounts, at times, exceeded federally insured limits. The Organization manages credit risk by maintaining these balances with high-quality financial institutions. The Organization has not experienced any losses in such accounts and believes it is not exposed to any significant credit risk.

**NOTE 10 – SUBSEQUENT EVENTS**

In preparing these financial statements, the Organization has evaluated events and transactions for potential recognition or disclosure through October 8, 2018, the date the financial statements were available to be issued. There were no additional subsequent events.