

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH
FINANCIAL STATEMENTS AND SUPPLEMENTARY INFORMATION
FOR THE TWELVE MONTHS ENDED DECEMBER 31, 2018
WITH COMPARATIVE TOTALS FOR 2017

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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, 2018, 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.

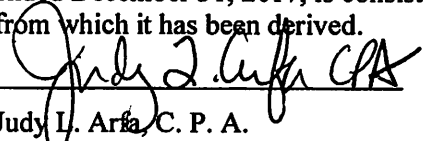
I believe that the audit evidence I have obtained is sufficient and appropriate to provide a basis for my audit opinion.

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, 2018, 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 2017 financial statements, and I expressed an unmodified audit opinion on those audited financial statements in my report dated October 8, 2018. In my opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2017, is consistent, in all material respects, with the audited financial statements from which it has been derived.



Judy L. Arfa, C. P. A.
Houston, Texas
August 31, 2019

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

STATEMENT OF FINANCIAL POSITION

DECEMBER 31, 2018
WITH COMPARATIVE TOTALS FOR 2017

| | <u>2018</u> | <u>2017</u> |
|---|-------------------|-------------------|
| Assets | | |
| Cash and cash equivalents | \$ 441,471 | \$ 734,887 |
| Accounts Receivable | 11,662 | 8,523 |
| Investments - short-term | <u>196,756</u> | <u>170,451</u> |
| Total Assets | <u>\$ 649,889</u> | <u>\$ 913,861</u> |
| Liabilities and Net Assets | | |
| Liabilities: | | |
| Accounts payable | \$ 20,508 | \$ 4,924 |
| Due to research foundations | <u>70,000</u> | <u>25,000</u> |
| Total Liabilities | <u>90,508</u> | <u>29,924</u> |
| Net Assets: | | |
| Without donor restrictions | <u>559,381</u> | <u>883,937</u> |
| Total Net Assets | <u>559,381</u> | <u>883,937</u> |
| Total Liabilities and Net Assets | <u>\$ 649,889</u> | <u>\$ 913,861</u> |

See accompanying notes to financial statements.

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

STATEMENT OF ACTIVITIES

YEAR ENDED DECEMBER 31, 2018 WITH COMPARATIVE TOTALS FOR 2017

| | Without Donor Restrictions | With Donor Restrictions | Totals 2018 | Totals 2017 |
|--|-------------------------------|----------------------------|-------------------|-------------------|
| Revenue, Gains, and Other Support | | | | |
| Merchandise sales | \$ 2,422 | \$ | \$ 2,422 | \$ 3,046 |
| Cost of goods sold | (1,549) | | (1,549) | (680) |
| Net | <u>873</u> | | <u>873</u> | <u>2,366</u> |
| Contributions | 177,261 | | 177,261 | 177,950 |
| Contributions in-kind | 265,766 | | 265,766 | 309,870 |
| Family conference income | 71,000 | | 71,000 | 0 |
| Special events | 270,176 | | 270,176 | 167,606 |
| Investment revenue | (2,773) | | (2,773) | 34,702 |
| Other revenues | 806 | | 806 | 0 |
| Total Revenue, Gains, and Other Support | <u>783,109</u> | | <u>783,109</u> | <u>692,494</u> |
| Expenses | | | | |
| Program service expenses | 474,490 | | 474,490 | 316,362 |
| Research grants | 558,849 | | 558,849 | 214,875 |
| Supporting services | 5,154 | | 5,154 | 6,689 |
| Fundraising | 69,172 | 0 | 69,172 | 56,177 |
| Total Expenses | <u>1,107,665</u> | | <u>1,107,665</u> | <u>594,103</u> |
| Increase (decrease) in net assets | <u>(324,556)</u> | | <u>(324,556)</u> | <u>98,391</u> |
| Net assets, beginning of year | <u>883,937</u> | | <u>883,937</u> | <u>785,546</u> |
| Net assets, end of year | <u>\$ 559,381</u> | <u>\$ 0</u> | <u>\$ 559,381</u> | <u>\$ 883,937</u> |

See accompanying notes to financial statements.

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2018
WITH COMPARATIVE TOTALS FOR 2017

| | Program Service Expenses | Research Grants | Supporting Services | Fundraising | 2018 Totals | 2017 Totals |
|------------------------|--------------------------------|--------------------|------------------------|---------------|------------------|----------------|
| Expenses | | | | | | |
| Postage | 2,801 | | | | 2,801 | 2,642 |
| Printing | 199 | | | | 199 | 274 |
| Supplies | 3,842 | | | | 3,842 | 1,353 |
| Conferences | 141,821 | | | | 141,821 | 8,321 |
| Insurance | 1,485 | | 302 | 730 | 2,517 | 2,482 |
| Value-volunteer hours* | 236,000 | | | | 236,000 | 285,000 |
| Research grants | | 558,849 | | | 558,849 | 214,875 |
| Business expenses | 339 | | | | 339 | 392 |
| Business registration | | | | 135 | 135 | 70 |
| Professional fees | 79,358 | | | | 79,358 | 4,030 |
| In-kind expenses *** | | | | 29,366 | 29,366 | 24,870 |
| Bank charges | | | 3,915 | | 3,915 | 5,032 |
| Telephone | 402 | | 67 | 201 | 670 | 1,547 |
| Family support | 2,099 | | | | 2,099 | 136 |
| Memberships & dues | 1,084 | | | | 1,084 | 0 |
| Gifts-Volunteers | 832 | | | | 832 | 1,301 |
| Event expenses | | | | 34,647 | 34,647 | 23,601 |
| Donor management | 4,228 | | 735 | 4,228 | 9,191 | 14,177 |
| Storage-Samples | | | | | | 4,000 |
| Total Expenses | 474,490 | 558,849 | 5,154 | 69,172 | 1,107,665 | 594,103 |

* See page 12, Note 4

*** Fundraising events

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

STATEMENTS OF CASH FLOWS

YEAR ENDED DECEMBER 31, 2018 WITH COMPARATIVE TOTALS FOR 2017

| | <u>2018</u> | <u>2017</u> |
|--|-------------------|-------------------|
| Cash Flows From Operating Activities | | |
| Increase (decrease) in net assets | \$ (324,556) | \$ 98,391 |
| Adjustments to reconcile change in net assets to net cash provided (used) by operating activities: | | |
| Interest income on investments | (3,706) | (1,958) |
| Unrealized (gain) loss on investments | 6,913 | (31,823) |
| (Increase) Decrease in accounts receivable | (3,139) | (8,523) |
| Increase (Decrease) in accounts payable | 15,584 | 4,924 |
| Increase (Decrease) in amounts due to research foundations | 45,000 | 5,000 |
| Net Cash Provided (Used) by Operating Activities | <u>(263,904)</u> | <u>66,011</u> |
| Cash Flows From Investing Activities | | |
| Purchase of investments | <u>(29,512)</u> | <u>(39,281)</u> |
| Net Cash Provided (Used) by Investing Activities | <u>(29,512)</u> | <u>(39,281)</u> |
| | | |
| Net Change in Cash and Cash Equivalents | (293,416) | 26,730 |
| | | |
| Cash and cash equivalents, beginning of year | <u>734,887</u> | <u>708,157</u> |
| Cash and cash equivalents, end of year | <u>\$ 441,471</u> | <u>\$ 734,887</u> |
| | | |
| Cash and cash equivalents, without donor restrictions | <u>\$ 441,471</u> | <u>\$ 734,887</u> |
| Total cash and cash equivalents | <u>\$ 441,471</u> | <u>\$ 734,887</u> |

See accompanying notes to financial statements.

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND DECEMBER 31, 2017

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 ten-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, 2018 AND DECEMBER 31, 2017

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:

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 non-interest bearing demand accounts. Accounts are 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.

Investments – Investments in marketable debt and equity securities are reported at fair value. Net investment return (loss) consists of interest and dividend income, realized and unrealized gains and losses, less external and direct internal investment expenses. Net investment return is reported in the statement of activities as a change in net assets without donor restrictions unless the use of the income is limited by donor-imposed restrictions. Net investment return whose use is restricted by the donor is reported as an increase or decrease in net assets with donor restrictions.

Net asset classification – Net assets, revenue, gains and losses are classified based on the existence or absence of donor-imposed restrictions, as follows:

- Net assets without donor restrictions are available for use in general operations and are not restricted by donor-imposed stipulations, even though their use may be limited in other respects, such as by contract or board designation.
- Net assets with donor restrictions are subject to donor-imposed restrictions. Some restrictions are temporary in nature, such as those that will be met by the passage of time or use for a purpose specified by the donor. Other restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. Donor-imposed restrictions are released when the stipulated time has elapsed, the stipulated purpose has been fulfilled, or both. Contributions of long-lived assets and of cash restricted for the acquisition of long-lived assets are released when the assets are placed in service. Donor-restricted endowment earnings are released when those earnings are appropriated in accordance with spending policies and are used for their restricted purpose.

INTERNATIONAL FOUNDATION FOR CDKLS RESEARCH

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND DECEMBER 31, 2017

NOTE 2 – SIGNIFICANT ACCOUNTING POLICIES (CONT.)

Contributions are recognized as revenue at fair value when an unconditional commitment is received from the donor. Contributions received with donor stipulations that limit their use are classified as restricted support.

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 net assets without donor restrictions or net assets with donor restrictions 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 medications to treat injuries) or implicit (such as gifts received in a capital improvements drive or in an appeal for a particular program).

Contributions Whose Restrictions Are Met in the Same Year - Restricted contributions may be reported as support without donor restrictions 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 a contribution without donor restrictions 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 contributions with donor restrictions of \$25,000 and contributions without donor restrictions of \$25,000.

Designations Imposed Internally - Sometimes, the Board of directors may designate a portion of net assets without donor restrictions 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 future acquisitions. 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, 2018 AND DECEMBER 31, 2017

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)(vi).

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.

Functional Expense Allocation – The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities. The majority of expenses can generally be directly identified with the program or supporting services to which they relate and are charged accordingly. Other expenses by function have been allocated among program and supporting service classifications on the basis of salaries, time sheets, and other methods determined by management.

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND DECEMBER 31, 2017

NOTE 3 – CASH AND CASH EQUIVALENTS

Cash and cash equivalents as of December 31, 2018 and December 31, 2017 consisted of the following:

| | <u>2018</u> | | <u>2017</u> | |
|--------------------|-------------------|-------------------|-------------------|-------------------|
| | <u>Cost</u> | <u>Fair Value</u> | <u>Cost</u> | <u>Fair Value</u> |
| Checking | \$ 342,486 | \$ 342,486 | \$ 314,759 | \$ 314,759 |
| Money market funds | <u>98,985</u> | <u>98,985</u> | <u>420,128</u> | <u>420,128</u> |
| Total | <u>\$ 441,471</u> | <u>441,471</u> | <u>\$ 734,887</u> | <u>\$ 734,887</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 \$236,000 for the year ending December 31, 2018 and \$285,000 for the year ending December 31, 2017. This amount is reflected in the financial statements.

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, 2018 and December 31, 2017 is \$29,766 and \$24,870, respectively.

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND DECEMBER 31, 2017

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, 2018 and December 31, 2017 consisted of the following:

| | <u>2018</u> | | <u>2017</u> | |
|----------|-------------------------------------|-------------------|-------------------------------------|------------------|
| | Significant Observable Inputs | | Significant Observable Inputs | |
| | <u>Fair Value</u> | <u>Level 2</u> | <u>Fair Value</u> | <u>Level 2</u> |
| Equities | \$ 196,756 | \$ 196,756 | \$170,451 | \$170,451 |
| Total | <u>\$ 196,756</u> | <u>\$ 196,756</u> | <u>\$170,451</u> | <u>\$170,451</u> |

Return on investment is as follows for the years ending December 31, 2018 and December 31, 2017.

| | <u>2018</u> | <u>2017</u> |
|-----------------------------|------------------|------------------|
| Interest/Dividend Income | \$ 3,706 | \$ 1,958 |
| Contributions of Securities | 29,512 | 39,281 |
| Unrealized gains (losses) | <u>(6,913)</u> | <u>31,823</u> |
| Total | <u>\$ 26,305</u> | <u>\$ 73,062</u> |

NOTE 7 – AMOUNTS DUE TO RESEARCH FOUNDATIONS

Amounts due to research foundations at December 31, 2018 and December 31, 2017 consist of the following:

| | <u>2018</u> | <u>2017</u> |
|---------------------------|------------------|------------------|
| Due in less than one year | <u>\$ 70,000</u> | <u>\$ 25,000</u> |
| Total amounts due | <u>\$ 70,000</u> | <u>\$ 25,000</u> |

INTERNATIONAL FOUNDATION FOR CDKL5 RESEARCH

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND DECEMBER 31, 2017

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, 2017, 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 August 31, 2019, the date the financial statements were available to be issued. There were no additional subsequent events.

NOTE 11 – NET ASSETS WITHOUT DONOR RESTRICTIONS

Net assets without donor restrictions are composed of the following:

| | <u>2018</u> |
|---|------------------|
| Undesignated | <u>\$559,381</u> |
| Total net assets without donor restrictions | <u>\$559,381</u> |