# FOUNDATION FOR ANGELMAN SYNDROME THERAPEUTICS FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2019 AND 2018

# FOUNDATION FOR ANGELMAN SYNDROME THERAPEUTICS TABLE OF CONTENTS DECEMBER 31, 2019

	Pages
INDEPENDENT AUDITOR'S REPORT	1 – 2
STATEMENTS OF FINANCIAL POSITION	3
STATEMENTS OF ACTIVITIES	4 – 5
STATEMENTS OF CASH FLOWS	6
NOTES TO FINANCIAL STATEMENTS	7 – 16

600 ENTERPRISE DRIVE SUITE 109 OAK BROOK, IL 60523

6200 PHONE 219.769.6000

PHONE 312.345.6200 FAX 312.345.6210

FAX 219.769.6036

518 EAST 86<sup>TH</sup> AVENUE

MERRILLVILLE, IN 46410

#### INDEPENDENT AUDITOR'S REPORT

To the Officers and Directors Foundation for Angelman Syndrome Therapeutics Downers Grove, IL

## **Report on the Financial Statements**

We have audited the accompanying financial statements of the Foundation for Angelman Syndrome Therapeutics (a nonprofit organization), which comprise the statements of financial position as of December 31, 2019 and 2018, 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. 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.

## **Auditor's Responsibility (Continued)**

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 except as noted below, the financial statements referred to above present fairly, in all material respects, the financial position of the Foundation for Angelman Syndrome Therapeutics as of December 31, 2019 and 2018, 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.

#### **Other Matter**

As disclosed in Note 5 of the financial statements, accounting principles generally accepted in the United States of America require that investments in which there is significant control and a majority ownership over fifty percent prepare consolidated financial statements. The accompanying financial statements only report the activity of the Foundation of Angelman Syndrome Therapeutics. The investment is recorded using the equity method of accounting.

Hegre, McMahon & Schimmel, LLC

Oak Brook, Illinois August 25, 2020

# FOUNDATION FOR ANGELMAN SYNDROME THERAPEUTICS STATEMENTS OF FINANCIAL POSITION DECEMBER 31, 2019 AND 2018

	2019	 2018
ASSETS		
Cash and cash equivalents	\$ 2,042,555	\$ 1,623,071
Investments at fair value	7,994,350	7,278,795
Investment in GeneTx Biotherapeutics, LLC	 1,968,564	-
TOTAL ASSETS	\$ 12,005,469	\$ 8,901,866
LIABILITIES AND NET ASSETS		
Current Liabilities		
Accounts payable	\$ 42,182	\$ 154,001
Accrued expenses	14,875	-
Grants payable, net of discounted rate to present value of \$26,244		
and \$8,635 for 2019 and 2018, respectively	 1,794,345	 1,174,132
Total current liabilities	1,851,402	1,328,133
Grants payable, net of discounted rate to present value of \$49,674		
and \$ - for 2019 and 2018, respectively	1,403,030	
TOTAL LIABILITIES	 3,254,432	1,328,133
Net Assets		
Without donor restrictions	8,735,447	7,558,143
With donor restrictions	 15,590	 15,590
TOTAL NET ASSETS	8,751,037	7,573,733
TOTAL LIABILITIES AND NET ASSETS	\$ 12,005,469	\$ 8,901,866

# FOUNDATION FOR ANGELMAN SYNDROME THERAPEUTICS STATEMENTS OF ACTIVITIES FOR THE YEAR ENDED DECEMBER 31, 2019

	Without Donor Restrictions	With Donor Restrictions	Total		
REVENUES AND OTHER SUPPORT					
General donations	\$ 3,808,280	\$ -	\$ 3,808,280		
Special event revenues	385,874	-	385,874		
Investment income	135,974	-	135,974		
Realized gain / (loss) on investments	5	-	5		
Other income	6,739	-	6,739		
Net assets released from restriction	-		<del>-</del>		
Total revenues and other support	4,336,872	-	4,336,872		
EXPENSES					
Program expenses					
ABOM director salary	27,047	-	27,047		
Professional fees	10,299	-	10,299		
Costs of direct benefits to donors	566,254	-	566,254		
Payroll and payroll taxes	34,717	-	34,717		
Video and production  Advertising and promotion	36,750 9,578	-	36,750 9,578		
Travel scholarships	29,490	-	29,490		
Education and awareness	20,743	- -	20,743		
Research funding	4,126,259		4,126,259		
Total program expenses	4,861,137	-	4,861,137		
Supporting services  Management and general					
Bank and merchant account fees	350	-	350		
Computer and software expenses	13,889	-	13,889		
Filing fees and registrations	- 920	-	- 920		
Insurance Office supplies	829 2,131	-	829 2,131		
Payroll and payroll taxes	34,717	_	34,717		
Postage and delivery	649	_	649		
Professional fees	17,157	_	17,157		
Telephone	5,501	-	5,501		
Travel	8,715	-	8,715		
Fundraising expenses	183,057		183,057		
Total support services	266,995		266,995		
Total expenses	5,128,132		5,128,132		
Change in net assets from operations	(791,260)	-	(791,260)		
Nonoperating activities					
Net change in value of investment	1,968,564		1,968,564		
Change in net assets	1,177,304		1,177,304		
<b>NET ASSETS</b> , beginning of year	7,558,143	15,590	7,573,733		
<b>NET ASSETS</b> , end of year	\$ 8,735,447	\$ 15,590	\$ 8,751,037		

# FOUNDATION FOR ANGELMAN SYNDROME THERAPEUTICS STATEMENTS OF ACTIVITIES FOR THE YEAR ENDED DECEMBER 31, 2018

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUES AND OTHER SUPPORT General donations Special event revenues Investment income Realized gain / (loss) on investments Net assets released from restriction	\$ 5,013,988 321,782 80,450 (6,439) 21,351	\$ 21,351 - (21,351)	\$ 5,035,339 321,782 80,450 (6,439)
Total revenues and other support	5,431,132	-	5,431,132
EXPENSES  Program expenses  Director travel  Costs of direct benefits to donors  Education and awareness  Research funding  Total program expenses	12,000 401,048 1,205 2,260,991 2,675,244	- - - -	12,000 401,048 1,205 2,260,991 2,675,244
Supporting services  Management and general  Bank and merchant account fees  Computer and software expenses Filing fees and registrations Insurance  Office supplies Payroll and payroll taxes Postage and delivery Professional fees Telephone and telecommunications	658 11,657 8,400 5,229 2,030 62,046 1,370 125,248 5,583	- - - - - -	658 11,657 8,400 5,229 2,030 62,046 1,370 125,248 5,583
Travel Fundraising expenses	3,905 203,437	- -	3,905 203,437
Total support services	429,563		429,563
Total expenses	3,104,807		3,104,807
Change in net assets	2,326,325	-	2,326,325
NET ASSETS, beginning of year NET ASSETS, end of year	5,231,818 \$ 7,558,143	15,590 \$ 15,590	5,247,408 \$ 7,573,733

# FOUNDATION FOR ANGELMAN SYNDROME THERAPEUTICS STATEMENTS OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2019 and 2018

	2019	2018
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 1,177,304	\$ 2,326,325
Adjustments to reconcile change in net assets to net cash provided by		
operating activities		
Net realized and unrealized (gains) losses on investments	(5)	6,439
Income from investee	(1,968,564)	-
In-kind stock donations	(9,140)	-
Increase (decrease) in liabilities		
Accounts payable	(111,819)	151,301
Accrued expenses	14,875	-
Grants payable	2,023,243	(1,288,763)
Net cash provided by operating activities	1,125,894	1,195,302
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of investments	(720,224)	(5,671,697)
Proceeds from sale of investments	13,814	51,159
Net change in loan receivables	 <u>-</u>	3,000
Net cash used in investing activities	 (706,410)	 (5,617,538)
CHANGE IN CASH AND CASH EQUIVALENTS	419,484	(4,422,236)
Cash and cash equivalents, beginning of year	1,623,071	6,045,307
CASH AND CASH EQUIVALENTS, END OF YEAR	\$ 2,042,555	\$ 1,623,071

#### 1. NATURE OF ACTIVITIES

The Foundation for Angelman Syndrome Therapeutics ("the Foundation") was incorporated under the laws of the state of California on August 19, 2008, as a not-for-profit corporation for educational and other purposes and is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code. Over the years, the Foundation has endowed several medical grants and research programs targeted at finding treatments and a cure to the neurological disorder of Angelman Syndrome. Their main sources of revenue come from donations from individuals, foundations, and corporations and ticket sales and sponsorships for the Foundation's annual gala.

### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### Financial Statement Presentation

The financial statements of the Foundation have been prepared in accordance with accounting principles generally accepted in the United States of America ("GAAP"), which require the Foundation to report informational regarding its financial position and activities according to the following net asset classifications:

**Net assets without donor restrictions:** Net assets that are not subject to donor-imposed restrictions and may be expended for any purpose in performing the primary objectives of the organization. These net assets may be used at the discretion of the Foundation's management and the board of directors.

**Net assets with donor restrictions:** Net assets subject to stipulations imposed by donors, and grantors. Some donor restrictions are temporary in nature; those restrictions will be met by actions of the Foundation or by the passage of time. Other donor restrictions are perpetual in nature, where by the donor has stipulated the funds be maintained in perpetuity.

Donor restricted donations are reported as increases in net assets with donor restrictions. When a restriction expires, net assets are reclassified from net assets with donor restrictions to net assets without donor restrictions in the statements of activities. Donations that are donor-restricted for which the restriction is satisfied in the same reporting period are classified as without donor restrictions.

### Cash and Cash Equivalents

The Foundation's cash consists of cash on deposit with banks. Cash equivalents represent money market funds or short-term investments with original maturities of three months or less from the date of purchase.

## 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

#### Concentrations of Credit Risk

Financial instruments that potentially subject the Foundation to concentrations of credit risk consist principally of cash and cash equivalents and investments. The Foundation maintains its cash and cash equivalents in various bank accounts that, at times, may exceed federally insured limits. The Foundation's cash and cash equivalent accounts have been placed with high credit quality financial institutions. The Foundation has not experienced, nor does it anticipate, any losses with respect to such accounts.

#### Investments

Investments are reported at cost, if purchased, or at fair value, if donated. Thereafter, investments are reported at their fair values in the statements of financial position, and changes in fair value are reported as investment return in the statements of activities.

Purchases and sales of securities are reflected on a trade-date basis. Gains and losses on sales of securities are based on average cost and are recorded in the statements of activities in the period in which the securities are sold. Interest is recorded when earned. Dividends are accrued as of the ex-dividend date.

# Fair Value of Financial Instruments

The carrying amount of financial instruments, accounts payable and accrued expenses approximate fair value due to the short maturity of these instruments.

Fair value is defined as the price that would be received to sell an asset in the principal or most advantageous market for the asset in an orderly transaction between market participants on the measurement date. Fair value should be based on the assumptions market participants would use when pricing an asset. GAAP establishes a fair value hierarchy that prioritizes investments based on those assumptions. The fair value hierarchy gives the highest priority to quoted prices in active markets (observable inputs) and the lowest priority to an entity's assumptions (unobservable inputs). The Foundation groups assets at fair value in three levels, based on the markets in which the assets and liabilities are traded and the reliability of the assumptions used to determine fair value. These levels are:

- Level 1 Unadjusted quoted market prices for identical assets or liabilities in active markets as of the measurement date.
- Level 2 Other observable inputs, either directly or indirectly, including:
  - ➤ Quoted prices for similar assets / liabilities in active markets;
  - ➤ Quoted prices for identical or similar assets in non-active markets;
  - ➤ Inputs other than quoted prices that are observable for the asset / liability; and,
  - ➤ Inputs that are derived principally from or corroborated by other observable market data.
- Level 3 Unobservable inputs that cannot be corroborated by observable market data.

## 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

#### **Donations**

Donations received are recorded as net assets without donor restrictions or net assets with donor restrictions, depending on the existence and / or nature of any donor-imposed restrictions. Donations that are restricted by the donor are reported as an increase in net assets without donor restrictions if the restriction expires in the reporting period in which the contribution is recognized. All other donor restricted donations are reported as an increase in net assets with donor restrictions, depending on the nature of restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions.

#### Special event revenues

Special event revenues consist of the fair market value of ticket sales for the Foundations one gala in December as well as sponsorships as related to the event. Special event revenues also consist of any income derived from the event such as silent auction funds and raffles. The donation portion of the ticket sales are recorded as donations.

#### **In-Kind Donations**

Several volunteers have made significant contributions of their time in furtherance of the Foundation's mission. These services were not reflected in the accompanying statements of activities because they do not meet the necessary criteria for recognition under GAAP.

### Functional Expenses

The costs of providing program and other activities have been included in the statements of activities. Accordingly, certain costs have been allocated among program and supporting services benefited as well as fundraising activities. Accordingly, costs associated with a specific program or supporting service have been charged directly to that program or supporting service. Costs that benefit more than one program or supporting service have been allocated among the programs and supporting services benefited based on an equitable basis. Payroll and payroll taxes and professional fees have been allocated based on time and effort. All other costs have been directly charged. Fundraising costs are summarized in the statements of activities while program and management and general expenses have been broken out.

### **Grants Payable**

Grants authorized but unpaid at year end are reported as liabilities in accordance with SFAS No. 116, *Accounting for Contributions Received and Contributions Made*. Grants to be paid in more than one year are discounted using the long term federal rate applicable at December 31, 2019 and 2018, respectively.

## 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

## Use of Estimates

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

#### Income Taxes

The Foundation is exempt from income tax under IRC section 501(c)(3), though it is subject to tax on income unrelated to its exempt purpose, unless that income is otherwise excluded by the Code. The Foundation has processes presently in place to ensure the maintenance of its tax-exempt status; to identify and report unrelated income; to determine its filing and tax obligations in jurisdictions for which it has nexus; and to identify and evaluate other matters that may be considered tax positions. The Foundation has determined that there are no material uncertain tax positions that require recognition or disclosure in the financial statements as of December 31, 2019 and 2018.

## Reclassifications

Certain amounts as previously reported in the December 31, 2018 financial statements have been reclassified to conform to the December 31, 2019 presentation. Such reclassifications have no effect on reported amounts of net assets or change in net assets.

## Recent Accounting Guidance

In June 2018, the Financial Accounting Standards Board (FASB) issued Accounting Standard Updated (ASU) 2018-08, *Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made.* The amendments in this update will assist entities in evaluating whether transactions should be accounted for as contributions (nonreciprocal transactions) or as exchange (reciprocal) transactions and determining whether a transaction is conditional. The Foundation adopted ASU 2018-08 on January 1, 2019 using the modified retrospective approach. Adoption of ASU 2018-08 resulted in no transition adjustment being required.

### 3. LIQUIDITY AND AVAILABILITY OF RESOURCES

The following represents the Foundation's financial assets at December 31, 2019 and 2018:

Financial assets at year-end:	2019		 2018
Cash and cash equivalents	\$	2,042,555	\$ 1,623,071
Investments, at fair value		7,994,350	7,278,795
Total financial assets		10,036,905	8,901,866

## 3. LIQUIDITY AND AVAILABILITY OF RESOURCES (continued)

		2019		2018
Less amounts not available to be used within one	year:			
Net assets with donor restrictions	\$	15,590	\$	15,590
Board approved grants payable		1,794,345		1,174,132
		1,809,935		1,189,722
Financial assets available to meet general expenditures over the next twelve months	<u>\$</u>	8,226,970	<u>\$</u>	7,712,144

The Foundation's goal is generally to maintain financial assets to meet 90 days of operating expenses (approximately \$100,000). As part of its liquidity plan, excess cash is invested in short-term investments and the Foundation keeps around \$200,000 - \$300,000 in their operating account. The Investment in GeneTx Biotherapeutics, LLC is not included in the calculation as the Foundation does not have access to cash from the investment nor do they have plans on selling their shares by the end of 2020.

#### 4. INVESTMENTS AT FAIR VALUE

The following table summarizes the investments as of December 31, 2019:

	Level 1	Level	2	Level 3	3	N	4V	Total
Fixed Income	\$ 7,994,350	\$	-	\$	-	\$	-	\$ 7,994,350

The following table summarizes the investments as of December 31, 2018:

	Level 1	Level 2	_	Lev	el 3	N	AV	Total
Fixed Income	\$ 7,278,795	\$	-	\$	-	\$	-	\$ 7,278,795

## 5. INVESTMENT USING THE EQUITY METHOD

In 2017, the Foundation invested \$500,000 in GeneTx Biotherapeutics, LLC (GeneTx), a forprofit limited liability company. In 2018, the Foundation invested an additional \$1,264,239 in GeneTx. With these investments, the Foundation owns approximately 58% of the member units of GeneTx. Over 50% ownership in an LLC requires financial statements to be consolidated; however, the Foundation has elected to use to equity method to value the investment. The balance sheet and income statement, in aggregate, of GeneTx is presented below for the years ended December 31, 2019 and 2018, respectively.

	2019	2018
Total Assets	\$ 18,477,121	\$ 1,261,319
Total Liabilities	\$ 4,293,075	\$ 621,888
Net Loss	\$ 9,138,804	\$ 3,632,878

### 5. INVESTMENT USING THE EQUITY METHOD (continued)

Under the equity method, the investment is initially recorded at cost then reduced by dividends and increased or decreased by the Foundation's proportionate share of the investee's net earnings or loss.

During 2019, an unrelated third party entered into an option agreement with GeneTx to acquire all of the units of the company. Under the terms of the agreement, the unrelated third party made an upfront option payment in 2019 of \$20,000,000. This payment was paid directly to GeneTx but was deemed to have been paid to each unit holder and recontributed to GeneTx as a capital contribution. The Foundation's deemed contribution amount was \$11,865,527. No additional units of GeneTx were received as a result of this transaction. Losses allocated to the Foundation for 2019 were \$9,896,963. For the year ended December 31, 2019, the value of the investment using the equity method was \$1,968,564.

During 2018, the investment in GeneTx increased for tax purposes as a result of investments from outside parties and a step-up in the book basis due to the outside investments. The tax loss generated from the investment in GeneTx during 2018 exceeded its cumulative investments. As a result, the investment in GeneTx has been written down to zero as of December 31, 2018 as management does not feel that it is appropriate to reflect a negative investment in the financial statements as of December 31, 2018.

In February 2020, the unrelated third party made an additional \$25,000,000 payment to extend the option period. This payment was paid directly to GeneTx but was deemed to have been paid to each unit holder and recontributed to GeneTx as a capital contribution. No additional units of GeneTx were received as a result of this transaction.

#### 6. NET ASSETS

Net assets with donor restrictions were as follows for the years ended December 31, 2019 and 2018:

		2019	 2018
Specific Purpose			
Clinical Trial Travel	\$	15,590	\$ 15,590
Net assets released from net assets with donor restrict	tions are	as follows:	
Satisfaction of Purpose Restrictions		2019	2018
Grants	\$		\$ 21,351

### 7. GRANTS AND GRANTS PAYABLE

In 2013, the Foundation pledged a Grant of \$635,979 for research costs payable over one year to the University of South Florida for the identification and characterization of novel therapeutics for Angelman Syndrome. All amounts for the pledge have been paid out as of the end of 2013. In 2014, the Foundation pledged an additional \$797,468 toward this grant. All amounts for the additional pledge have been paid out as of the end of 2014. In 2015, the Foundation pledged an additional \$971,284 toward this grant. All amounts for the additional pledge have been paid out as of the end of 2015. In 2016, the Foundation pledged an additional \$2,209,231 toward this grant. All amounts for the additional pledge have been paid out as of the end of 2016. In 2017, the Foundation pledged an additional \$2,041,953 toward this grant. \$1,579,751 of the pledged amount has been paid out as of the end of 2017. In 2018, the Foundation paid out the remaining grant payable from 2017. In 2018, The Foundation pledged an additional \$165,000 toward this grant. This grant has been fully funded prior to the end of 2019. As such, no discounting of this grant has been done to present this grant at a present value amount.

In 2014, the Foundation pledged a Grant of \$150,000 for the production of a pig model and research items to Texas A&M. As of December 31, 2014, the balance remained outstanding. All amounts for the pledge were paid out as of the end of 2015. In 2016, the Foundation pledged an additional \$220,704 toward this grant. All amounts for the additional pledge have been paid out as of the end of 2016. In 2017, the Foundation pledged an additional \$1,261,240 toward this grant. None of the pledged amount was paid out as of the end of 2017. In 2018, the Foundation paid out the remaining grant payable from 2017. In 2018, The Foundation pledged an additional \$810,407 toward this grant. This grant has been fully funded prior to the end of 2018.

In 2016, the Foundation pledged a Grant of \$479,252 for an imaging equipment upgrade and for the analysis of therapeutic proteins to the University of California Davis. All amounts for the pledge were paid out as of the end of 2016. In 2017, the Foundation pledged an additional \$297,390 toward this grant. \$287,397 of the pledged amount has been paid out as of the end of 2017. In 2018, the Foundation paid out the remaining grant payable from 2017. In 2018, the Foundation received a refund of the grant in the amount of \$32,096.

In 2017, the Foundation pledged a Grant of \$1,492,200 for clinical candidate development to the University of Pennsylvania. \$765,240 of this pledge was paid out as of the end of 2017. In 2018, the Foundation paid out an additional \$436,176 toward this grant. This grant has been fully funded in 2019. As such, no discounting of this grant has been done to present this grant at a present value amount.

In 2018, the Foundation pledged a Grant of \$352,292 for a gene therapy study using mice to the University of California Davis. \$202,292 of this pledge was paid out as of the end of 2018. This grant has been fully funded in 2019. As such, no discounting of this grant has been done to present this grant at a present value amount.

#### 7. GRANTS AND GRANTS PAYABLE (continued)

In 2018, the Foundation pledged a Grant of \$397,040 for a ketone supplement human clinical trial to the Vanderbilt University Medical Center. All amounts for the pledge have been paid out as of the end of 2018.

In 2018, the Foundation pledged a Grant of \$212,730 for a ketone supplement human clinical trial to the Baylor College of Medicine. None of this pledge was paid out as of the end of 2018. This grant has been fully funded in 2019. As such, no discounting of this grant has been done to present this grant at a present value amount.

In 2018, the Foundation pledged a Grant of \$355,618 for an outcome measure study to Duke University. None of this pledge was paid out as of the end of 2018. This grant is to be paid out over a two-year period of time. As of December 31, 2019, the grant had a balance owed of \$92,046 which was paid in full in 2020.

In 2019, the Foundation pledged a Grant of \$1,111,112 for translation research in a pig model of Angelman Syndrome to Texas A&M University. None of this pledge was paid out as of the end of 2019. This grant is to be paid out over a four-year period of time; therefore, this pledge was discounted accordingly to the present value amount using the U.S. Treasury long term adjusted rate at the time the pledge was authorized (1.59%) plus a risk free rate of .5% totaling 2.09%. The amount discounted was \$49,595.

In 2019, the Foundation pledged a Grant of \$1,224,303 as an infrastructure grant to the University of California-Davis. None of this pledge was paid out as of the end of 2019. The grant is to be paid over a two-year period of time; therefore, the pledge was discounted accordingly to the present value amount using the U.S. Treasury long term adjusted rate at the time the pledge was authorized (1.59%) plus a risk free rate of .5% totaling 2.09%. The amount discounted was \$26,323. The entire grant was for a five year period for \$2,957,127; however, only the first two years have been board approved. The remaining three years will be approved by the board on a year-by-year basis.

In 2019, the Foundation pledged a Grant of \$838,866 for a clinical candidate development to the University of Pennsylvania. \$209,614 was paid out during 2019 with \$629,252 remaining to be paid out as of December 31, 2019. This grant is expected to be paid in full in 2020. As such, no discounting of this grant has been done to present this grant at a present value amount.

In 2019, the Foundation pledged a Grant of \$75,000 for a pilot feasibility study of an enzyme replacement therapy to the University of California-Davis. None of this pledge was paid out as of the end of 2019. This grant has been fully funded in 2020. As such, no discounting of this grant has been done to present this grant at a present value amount.

In 2019, the Foundation pledged a Grant of \$75,000 for a rodent study of non-snord 116 paternal activation to the University of California-Davis. None of this pledge was paid out as of the end of 2019. This grant has been fully funded in 2020. As such, no discounting of this grant has been done to present this grant at a present value amount.

# 7. GRANTS AND GRANTS PAYABLE (continued)

	2019	2018
Total grants payable	\$ 3,273,293	\$ 1,182,767
Less: Discount rate to present value	75,918 3,197,375	8,635 1,174,132
Less: Grants payable within one year, net of discount rate	1,794,345	1,174,132
Net Long-Term Grants Payable	\$ <u>1,403,030</u>	\$

Aggregate maturities of grants payable are as follows:

# Year ending December 31

2020	\$ 1,794,345
2021	830,587
2022	250,408
2023	322,035
Total	\$ 3,917,375

#### 8. Concentrations

For the year ended December 31, 2019, one individual accounted for 26% of total donations provided to the Foundation. This individual did not make a donation in 2018.

### 9. SUBSEQUENT EVENTS

The Foundation evaluated subsequent events through August 25, 2020, the date these financial statements were available to be issued. Management has determined that no events or transactions, except as noted below and in Note 5, have occurred subsequent to the statement of financial position date that require additional disclosure in the financial statements.

On January 30, 2020, the World Health Organization declared the coronavirus outbreak a "Public Health Emergency of International Concern" and on March 11, 2020 declared it to be a pandemic. Actions taken around the world to help mitigate the spread of the coronavirus include restrictions on travel, quarantines in certain areas, and forced closures for certain type of public places and businesses. The coronavirus and actions taken to mitigate it have had and are expected to continue to have an adverse impact on the economies and financial markets of many countries, including the geographical area in which the Foundation operates. While it is unknown how long these conditions will last and what the complete financial effect will be to the Company, to date, the Foundation is expected to have net losses of around \$1 million from revenue typically received from their annual gala that will be canceled in 2020.