



# **FINANCIAL REPORT**

# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

YEARS ENDED JUNE 30, 2019 AND 2018

# FINANCIAL REPORT YEARS ENDED JUNE 30, 2019 AND 2018

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#### INDEPENDENT AUDITORS' REPORT

To the Board of Directors Osteogenesis Imperfecta Foundation, Inc. Gaithersburg, Maryland

#### **Report on the Financial Statements**

We have audited the accompanying financial statements of Osteogenesis Imperfecta Foundation, Inc., which comprise the statements of financial position as of June 30, 2019 and 2018, and the related statements of activities and changes in net assets, functional expenses (for the year ended June 30, 2019 only) 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.

#### Auditors' 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 audits 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 auditors' 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 auditors consider 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 Osteogenesis Imperfecta Foundation, Inc. as of June 30, 2019 and 2018, and the results of its operations and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

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Thompson Greenspon

Fairfax, Virginia March 4, 2020

# STATEMENTS OF FINANCIAL POSITION JUNE 30, 2019 AND 2018

	2019	2018
ASSETS		
Current Assets		
Cash and cash equivalents	\$ 147,831	\$ 388,988
Contributions receivable, net	161,286	184,245
Contracts receivable	2,763	-
Investments	1,348,450	1,420,941
Prepaid expenses and other	48,726	66,209
Grants receivable		168,000
Total Current Assets	1,709,056	2,228,383
Fixed Assets		
Furniture and equipment	159,418	134,451
Accumulated depreciation	(122,478)	(111,605)
Net Fixed Assets	36,940	22,846
Other Assets		
Beneficial interest in assets held in perpetual trust	15,500	15,500
Deposits	6,762	6,762
Long-term contributions receivable, net		13,984
Total Other Assets	22,262	36,246
Total Assets	\$ 1,768,258	\$ 2,287,475

The Notes to Financial Statements are an integral part of these statements.

	2019		2018
LIABILITIES AND NET ASSETS			
Current Liabilities			
Accounts payable	\$	66,358	\$ 51,575
Accrued payroll liabilities		29,226	23,860
Deferred revenue		14,145	117,805
Grants payable		136,826	239,500
Related party payable		-	 15,256
Total Current Liabilities		246,555	447,996
Long-term Liabilities			
Long-term grants payable		25,000	 -
Total Liabilities		271,555	 447,996
Net Assets			
Net assets without donor restrictions		782,895	795,225
Net assets with donor restrictions		713,808	 1,044,254
Total Net Assets		1,496,703	 1,839,479

Total Liabilities and Net Assets	\$ 1,768,258	\$ 2,287,475
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### STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS YEARS ENDED JUNE 30, 2019 AND 2018

		2019		2018				
	Net Assets	Net Assets		Net Assets Net Assets				
	Without Donor	With Donor		Without Donor	With Donor			
	Restrictions	Restrictions	Total	Restrictions	Restrictions	Total		
Support and Revenue								
Contributions and grants	\$ 265,036	\$ 378,752	\$ 643,788	\$ 167,726	\$ 548,959	\$ 716,685		
Contract revenue	52,597	-	52,597	-	-	-		
Event revenue	636,732	59,538	696,270	577,273	33,827	611,100		
Investment income	97,560	-	97,560	122,447	-	122,447		
Direct mailing revenue	358,085	-	358,085	243,631	-	243,631		
Conference revenue	101,890	9,780	111,670	-	134,021	134,021		
In-kind contributions	47,077	-	47,077	48,116	-	48,116		
Net assets released from restrictions	778,516	(778,516)	-	559,105	(559,105)	-		
Total Support and Revenue	2,337,493	(330,446)	2,007,047	1,718,298	157,702	1,876,000		
Expenses								
Program services								
Conferences	399,291	-	399,291	87,927	-	87,927		
Education and support	466,034	-	466,034	421,938	-	421,938		
Research	554,887	-	554,887	450,842	-	450,842		
Public awareness	72,844		72,844	74,868		74,868		
Total Program Services	1,493,056	-	1,493,056	1,035,575	-	1,035,575		
Support services								
General and administration	417,769	-	417,769	455,019	-	455,019		
Fundraising	438,998		438,998	429,922		429,922		
Total Support Services	856,767	-	856,767	884,941	-	884,941		
Total Expenses	2,349,823		2,349,823	1,920,516		1,920,516		
Change in Net Assets	(12,330)	(330,446)	(342,776)	(202,218)	157,702	(44,516)		
Net Assets, beginning of year	795,225	1,044,254	1,839,479	997,443	886,552	1,883,995		
Net Assets, end of year	\$ 782,895	\$ 713,808	\$ 1,496,703	\$ 795,225	\$ 1,044,254	\$ 1,839,479		

The Notes to Financial Statements are an integral part of these statements.

#### STATEMENT OF FUNCTIONAL EXPENSES YEAR ENDED JUNE 30, 2019

	Program Services								
		Education		Public		General and			Overall
	Conferences	and Support	Research	Awareness	Total	Administration	Fundraising	Total	Total
Salaries and fringe benefits	\$ 142,738	\$ 221,893	\$ 111,274	\$ 59,814	\$ 535,719	\$ 277,288	\$ 151,602	\$ 428,890	\$ 964,609
Bank fees	¢,	÷ ==:,000	-	¢ 00,011	-	31,442	32	31,474	31,474
Consulting fees	-	-	22,116	-	22,116	-	-	- ,	22,116
Depreciation	1,687	2,564	1,294	674	6,219	3,606	1,681	5,287	11,506
Dues and subscriptions	<sup></sup> 11	2,076	8	4	2,099	23	· 11	34	2,133
Equipment rental and maintenance	292	443	224	116	1,075	623	3,237	3,860	4,935
Event expense	-	3,149	-	-	3,149	-	193,380	193,380	196,529
Grants and fellowships	-	136,040	237,292	2,411	375,743	-	-	-	375,743
Information technology and									
web support	3,229	41,771	6,619	532	52,151	7,180	3,941	11,121	63,272
Insurance	646	863	495	258	2,262	1,380	4,121	5,501	7,763
Interest expense	-	-	-	-	-	7,040	-	7,040	7,040
Licenses and permits	14	21	11	6	52	29	7,949	7,978	8,030
Meetings and conferences	228,628	9,629	149,112	322	387,691	5,319	315	5,634	393,325
Bad debt expense	-	-	-	-	-	3,000	-	3,000	3,000
Occupancy	11,572	17,589	8,877	4,620	42,658	24,734	11,527	36,261	78,919
Office supplies	3,264	4,961	2,504	1,303	12,032	6,976	3,376	10,352	22,384
Postage and delivery	99	1,744	401	40	2,284	212	8,272	8,484	10,768
Printing and duplicating	992	11,009	761	396	13,158	2,119	1,521	3,640	16,798
Professional fees	853	1,296	654	341	3,144	36,058	3,748	39,806	42,950
Survey	-	1,714	8,122	-	9,836	-	-	-	9,836
Telephone	1,190	2,169	1,271	470	5,100	2,518	2,481	4,999	10,099
Travel	335	1,416	980	42	2,773	223	16,521	16,744	19,517
In-kind expenses	3,741	5,687	2,872	1,495	13,795	7,999	25,283	33,282	47,077
Total Expenses	\$ 399,291	\$ 466,034	\$ 554,887	\$ 72,844	\$ 1,493,056	\$ 417,769	\$ 438,998	\$ 856,767	\$ 2,349,823

The Notes to Financial Statements are an integral part of this statement.

# STATEMENTS OF CASH FLOWS YEARS ENDED JUNE 30, 2019 AND 2018

	 2019	2018		
Cash Flows from Operating Activities				
Change in net assets	\$ (342,776)	\$	(44,516)	
Adjustments to reconcile change in net assets				
to net cash used by operating activities				
Depreciation	11,506		11,401	
Realized and unrealized gain on investments	(54,608)		(80,310)	
(Increase) Decrease in				
Contributions receivable, net	36,943		91,058	
Contracts receivable	(2,763)		-	
Grants receivable	168,000		-	
Prepaid expenses and other	17,483		(14,114)	
Increase (Decrease) in				
Accounts payable and accruals	20,149		(15,284)	
Deferred revenue	(103,660)		104,955	
Grants payable	 (77,674)		(84,904)	
Net Cash Used by Operating Activities	 (327,400)		(31,714)	
Cash Flows from Investing Activities				
Payments for the purchase of property	(25,600)		(5,292)	
Payments for the purchase of investments	(214,056)		(249,437)	
Proceeds from sale of investments	 341,155		539,339	
Net Cash Provided by Investing Activities	 101,499		284,610	
Cash Flows from Financing Activities				
Payments to related party, net	(15,256)		-	
Collections on behalf of and payable to related party	 		15,256	
Net Cash (Used) Provided by Financing Activities	 (15,256)		15,256	
Net (Decrease) Increase in Cash and Cash Equivalents	(241,157)		268,152	
Cash and Cash Equivalents, beginning of year	 388,988		120,836	
Cash and Cash Equivalents, end of year	\$ 147,831	\$	388,988	

The Notes to Financial Statements are an integral part of these statements.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 1. **DESCRIPTION OF THE FOUNDATION**

Osteogenesis Imperfecta Foundation, Inc. (the Foundation or OIF) is a Georgia non-stock corporation incorporated in 1970 with the primary purpose of improving the quality of life for people affected by the bone disorder osteogenesis imperfecta (OI) through research into treatments and a cure, education, awareness, and mutual support. The Foundation's headquarters are located in Gaithersburg, Maryland.

The underlying categories represent the major program areas of the Foundation.

#### Research

The Foundation funds grants to support research relevant to understanding and treating OI. Through the Michael Geisman Fellowship program, OIF's young investigator grant program named for the son of OIF Founder, Gemma Geisman, fellowships are awarded to post-doctoral trainees working on projects with clear relevance to OI. This past year, OIF awarded first year funding to Dr. Heeseog Kang from the National Institutes of Health, NIAMS. Dr. Kang's research was titled PEDF-PARy-CyclophilinA/B pathway modulates osteogenesis imperfecta.

OIF hosts an annual Scientific Meeting to bring together leaders in clinical and basic research on a single topic related to OI. In addition, the Foundation participates in numerous research meetings sponsored by other organizations, including the National Institutes of Health (NIH). Every third year, OIF joins other OI associations at the International Scientific Congress on OI.

A key activity for the Foundation continues to be the participation in the Brittle Bone Disorders Consortium (BBDC). OIF is responsible for providing education to medical professionals through materials and meetings designed to give the most up-to-date information on OI care and research. Through the support of the Foundation, supported Linked Clinical Research Centers (LCRC), and constituent participation, OIF was able to gather important information about individuals living with OI and form the foundation on which the BBDC was built. This is the only rare disease network at the NIH that is studying bone and specifically OI. Under the leadership of OIF Medical Advisory Council member, Dr. Brendan Lee of Baylor College of Medicine, the BBDC has completed seven studies and has several more in progress. More than 1,500 people have joined the BBDC Contact Registry and the Consortium continues to work with its partners including Tampa Shriners Hospital for Children, A.I. DuPont Hospital for Children, Cologne Hospital in Cologne, Germany, Baylor College of Medicine, Montreal Shriners Hospitals for Children, Chicago Shriners Hospitals for Children, Kennedy Kreiger Institute, Hospital for Special Surgery, Oregon Health and Science University and National Children's Medical Center. The clinical research in progress includes a Phase I drug study, a study on scoliosis in people with severe OI, pregnancy and OI, dentinogenesis imperfecta and other dental/craniofacial issues and OI, a biomarkers study, and a quality of life and OI study.

OIF continues to improve its web based "tool kit" called the Information for Medical Professionals, which was developed as part of the BBDC. The information center, located at www.oif.org/meded, covers information about OI, both issues that affect children and adults, and provides online resources for providers who see few OI patients. The site is also host to OIF podcasts (20 to date) on a variety of topics including: spine issues and basilar invagination in OI; dental; surgical interventions; pregnancy and OI; hearing loss and OI; mental health and the OI patient; treatment options for adults and children and an overview of the diagnosis and treatment of OI. The podcasts have been downloaded a total of 1,609 times during calendar year 2019, and are a very popular feature of OIF's medical professional educational outreach.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 1. **DESCRIPTION OF THE FOUNDATION** (continued)

#### **Research** (continued)

<u>Scientific Meetings</u> – OIF gathered more than one hundred scientists and researchers for the 18th Annual OIF Science Meeting on April 10-12, 2019. Dr. Joan Marini and Dr. Cathleen Raggio chaired the meeting titled Identifying Gaps in OI Research. Each year, the meeting attracts scientists interested in learning more about the latest in basic and clinical OI research, and how the information could ultimately benefit people living with OI. The Foundation continues to lead in providing opportunities for medical professionals and scientists to meet to discuss new and innovative treatments that may ultimately benefit any person living with OI. It is important to keep all researchers current with the most up-to-date research on treatments that physicians will potentially use with their patients.

OIF successfully co-sponsored a two-day meeting titled Mechanistic and Therapeutic Advances in Rare Skeletal Diseases at the American Society of Bone and Mineral Research (ASBMR) annual meeting in Montreal. The meeting held in September 2018 was chaired by Dr. Brendan Lee from Baylor College of Medicine and Dr. Maurizio Pacifici from Children's Hospital of Philadelphia. More than 400 people attended the meeting, which included two days of scientific presentations on rare bone diseases and two days of poster presentations by young investigators.

<u>OI Adult Health Initiative</u> – In fiscal year 2019, OIF funded the second year of the cardiopulmonary grant. This community-directed scientific committee led studies in direct response to the growing concern of pulmonary complications, especially in adults, of those in the OI community. The committee will work to determine the inherent cause of restrictive physiology (cardiopulmonary insufficiency) in people with OI so that treatments can be recommended and appropriate measurements for an accurate assessment of the restrictive physiology in OI patients can be defined by creating a standard normative reference for each OI type.

<u>Impact Grant Program</u> – In partnership with Children's Brittle Bone Foundation (CBBF), this annual competitive grant program was designed and established to provide funding for items that will significantly improve the quality of life for a person who has OI and who has limited financial resources. This past year, the Foundation was able to finance 36 families' (115 individuals') travel to the OIF National Conference. In addition to funding conference scholarships, funding was provided to nine families for a range of items including hearing aids, a wheelchair, and physical therapy.

OIF continues to take the lead in developing programs that provide opportunities for scientific collaboration, mutual support for persons living with OI, and access to the most up-to-date and medically verified information about OI.

#### Education and Support

The Foundation offers medically verified information related to OI. Topics include medical issues such as genetics, diagnosis and treatments. Additional topics focus on daily living strategies, school and employment. The Foundation's staff replies to requests for information via phone, internet, fax, social media and mail. Educational materials are available in print and electronically through the OIF website. Print materials include books, brochures, fact sheets and a quarterly newsletter. Electronic materials include a monthly email newsletter, and via the website, fact sheets, booklets and brochures. Information on OI is written for a variety of audiences including medical professionals, parents and other family members, children, adults who have OI, and school professionals. On average, 40,000 people use the website each month. Foundation staff and volunteers respond to more than 7,500 direct inquiries a year. Information from these contacts is used to assess the need for new resources.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 1. **DESCRIPTION OF THE FOUNDATION** (continued)

#### Education and Support (continued)

The Foundation sponsors a network of support groups across the United States. Support group activities provide opportunities for mutual support and increased community awareness. Currently, there are 38 active groups in 32 states. In addition, 26 volunteer resource people are active in 25 states.

#### Family Conference

The Foundation's principal educational event is the Biennial National Conference on OI. The conference brings together adults who have OI, parents, other family members and leading medical experts. This conference provides the opportunity for attendees to have face-to-face meetings with experienced physicians, learn about the latest research, and interact with other people who are affected by OI.

In July 2018, the Foundation held its 21st Biennial National Conference in Baltimore, Maryland, bringing together 25 world-class experts on OI and more than 600 individuals living with OI for three days of information, mutual support and fun. The conference began with OIF's third annual National Walk-n-Wheel for OI event that drew more than 200 walkers and wheelers showing their Unbreakable Spirit to the Baltimore National Aquarium. Local volunteers and partner organizations, like the Degna Spoldi Family Foundation, University of Kentucky Healthcare, and Mereo BioPharma helped make the event a true success. The next conference will be held in July 2020 in Omaha, Nebraska.

Since its launch in 2015, OIF's Regional Conference program has reached more than 1,200 members of the OI community, half of whom had never attended an OI event before. These one-day conferences feature educational sessions led by OI experts including OIF Medical Advisory Council members. In fiscal year 2019, the Foundation held two regional conferences - one in Los Angeles in November 2018 that attracted more than 120 people, and one in Chicago in April 2019 that attracted more than 100 people.

#### Public Awareness

OIF strives to build public awareness and generate additional support among people with OI, community organizations, government agencies, the public, school personnel and medical professionals. The Foundation has a public service announcement, and partners with related organizations such as The U.S. Bone & Joint Decade, the National Organization for Rare Disorders, the National Bone Health Alliance, the Rare Disease Patient Network, the National Health Council, committees/councils of the National Institutes of Health, and the OI Federation of Europe. In addition, OIF participates in Rare Disease Day activities, and sponsors OI Awareness Week each May. National Osteogenesis Imperfecta Awareness Week 2019 was May 4-11, 2019. Volunteers proclaimed OI Awareness Week in over 13 cities and states, and held multiple events nationwide. OIF celebrated Wishbone Day, the international OI Awareness Day, by sharing facts and information via social media every hour for a consecutive twelve hours. During OI Awareness Week 2019, OIF reached more than 200,000 people on Facebook and gained more than 100 new Facebook followers.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 1. **DESCRIPTION OF THE FOUNDATION** (continued)

#### Public Awareness (continued)

OIF manages four social networking sites and continues to offer, through its website www.oif.org, links to sites that might be helpful or interesting to parents and young people living with OI, in addition to sites that help older adults with OI manage their disorder throughout their life through mutual support. The Foundation also maintains an official OIF Facebook page that provides information and resources to all ages and is updated daily. Currently, the OIF Facebook page has 12,429 followers.

The Foundation is committed to advocating on behalf of people with OI. OIF has established an advocacy initiative, a grassroots effort focusing on educating legislators and their staff about OI and the priorities of the Foundation.

#### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### **Basis of Accounting**

The financial statements have been prepared on the accrual basis of accounting in accordance with generally accepted accounting principles. Accordingly, revenues are recognized when earned and expenses are recognized when incurred.

#### Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

#### **Cash and Cash Equivalents**

The Foundation considers all highly liquid instruments purchased with an original maturity of three months or less to be cash equivalents.

For purposes of the statements of cash flows, cash equivalents include all highly liquid debt instruments with original maturities of three months or less. The Foundation maintains its cash balances with various financial institutions which, at times, may exceed federally insured limits of \$250,000. The Foundation has not experienced any losses from such accounts.

Donated securities or other assets that have no donor-imposed restrictions and that are immediately converted into cash are classified as cash from operating activities. During the years ended June 30, 2019 and 2018, the Foundation received \$4,592 and \$7,829, respectively, in donated stock that was immediately converted into cash and recognized as cash from operating activities in the accompanying statements of cash flows.

#### Prepaid Expenses

The Foundation records expenses incurred in advance for general operations and the Biennial National Conference as prepaid expenses.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

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

#### **Contributions Receivable**

Contributions receivable represent amounts which have been promised but not yet received. Contributions receivable are recorded at the original value less an estimate of uncollectible contributions. Contributions due beyond one year are discounted to reflect the present value of the contributions receivable using the mid-term annual Applicable Federal Rate (AFR). There were no contributions due beyond one year at June 30, 2019. The AFR was 2.86 percent at June 30, 2018.

#### **Contracts Receivable**

Contracts receivable represent revenue recognized on fixed-price contracts that has not yet been received.

#### Grants Receivable

Revenue recognized but not received from the granting agency is reported as grants receivable in the accompanying statements of financial position

#### **Fixed Assets**

The Foundation has a capitalization policy for qualifying assets in excess of \$1,000. Furniture and equipment are reported at cost. Assets and capital lease purchases are depreciated over a three- to ten-year estimated life using the straight-line method. Depreciation expense for the years ended June 30, 2019 and 2018 was \$11,506 and \$11,401, respectively.

#### Investments

Investments are accounted for at fair market value with any unrealized gains and losses reported in the statements of activities and changes in net assets.

#### Fair Value

Financial Accounting Standards Board (FASB) Accounting Standards Codification (ASC) Topic 820, *Fair Value Measurements and Disclosures,* provides a framework for measuring fair value. That framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. Fair value focuses on the price that would be received to sell the asset or paid to transfer the liability regardless of whether an observable liquid market price existed (an exit price). The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (Level 1 measurements) and the lowest priority to unobservable inputs (Level 3 measurements). The three levels of the fair value hierarchy under FASB ASC 820 are described below:

Level 1 – inputs to the valuation methodology are based upon unadjusted quoted prices for identical assets or liabilities in active markets that the Foundation has the ability to access.

Level 2 – inputs to the valuation methodology include: quoted prices for similar assets or liabilities in active markets, quoted prices for identical or similar assets or liabilities in markets that are not active, inputs other than quoted prices that are observable for the asset or liability, and market-corroborated inputs. If the asset or liability has a specified (contractual) term, the Level 2 input must be observable for substantially the full term of the asset or liability.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

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

#### Fair Value (continued)

Level 3 – inputs to the valuation methodology are unobservable and significant to the fair value measurement. Level 3 assets and liabilities measured at fair value are based on one or more of three valuation techniques (market, cost, or income approach). The market approach evaluates prices and other relevant information generated by market transactions involving identical or comparable assets or liabilities. The cost approach evaluates the amount that would be required to replace the service capacity of an asset (i.e., replacement cost). The income approach uses techniques that convert future amounts to a single present amount based on market expectations (including present value techniques, option-pricing models, and lattice models).

The asset's or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. Valuation techniques used need to maximize the use of observable inputs and minimize the use of unobservable inputs.

The following describes the valuation methodologies used for assets measured at fair value. There have been no changes in the methodologies used at June 30, 2019 and 2018.

*Common stocks:* Common stocks are valued at the closing price reported in the active market in which the individual securities are traded.

*Corporate and municipal bonds:* Bonds are valued at the closing price reported in the active market in which the bond is traded.

The methods described above may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, while the Foundation believes its valuation methods are appropriate and consistent with other market participants, the use of different methodologies or assumptions to determine the fair value of certain financial instruments could result in a different fair value measurement at the reporting date.

#### **Grants Payable**

Research grants awarded prior to year end but not distributed are recorded as grants payable and expensed accordingly.

#### Deferred Revenue

The Foundation records income for conference fees which have been paid in advance as deferred revenue.

#### **Net Assets**

Net assets are reported by the Foundation in accordance with generally accepted accounting principles. Net assets, revenues, gains, and losses are classified based on the existence or absence of donor- or grantor-imposed restrictions. Accordingly, net assets and changes therein are classified and reported as follows:

*Net Assets Without Donor Restrictions*: Net assets available for use in general operations and not subject to donor (or certain grantor) restrictions. The Board of Directors has designated, from net assets without donor restrictions, net assets for future operations in accordance with the bylaws of the Foundation. For the years ended June 30, 2019 and 2018, the balance of the Board-designated net assets was \$782,895 and \$795,225, respectively.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

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

#### Net Assets (continued)

**Net Assets With Donor Restrictions:** Net assets subject to donor (or certain grantor) imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. Donor-imposed restrictions are released when a restriction expires, that is, when the stipulated time has elapsed, when the stipulated purpose for which the resource was restricted has been fulfilled, or both.

#### Contributions and Grants Revenue

The Foundation receives a portion of its revenue from contributions and grants. Contributions revenue is recognized when the funds are received. For cost-reimbursable grants, revenue is recognized when it is earned per the terms of the agreement. All other grants are accounted for as unconditional promises to give, and revenue is recorded in the year that the promises are made.

#### Contract Revenue

The Foundation receives a portion of its revenue from a fixed-price contract. Revenue on fixed-price contracts is recognized using the percentage-of-completion method. Anticipated losses on contracts accounted for under the percentage-of-completion method are recognized in the period they are deemed probable and can be reasonably estimated.

#### Event Revenue

The Foundation receives a portion of its revenue from events hosted throughout the country by related and unrelated individuals and organizations. An event coordinator is available at the Foundation headquarters to help plan the event as well as answer questions the sponsoring individual or organization may have. The Foundation provides event training, which includes on-site collection of revenue. Revenue from these events is collected by the sponsoring individual or organization, which then remits that revenue to the Foundation. The Foundation's website and lockbox provide assistance to the sponsors in collection of revenue.

#### Functional Allocation of Expenses

The financial statements report certain categories of expenses that are attributable to more than one program or supporting function. Therefore, these expenses require allocation on a reasonable basis that is consistently applied. The expenses that are allocated include occupancy, depreciation, insurance, compensation and benefits, and other expenses, and are allocated on the basis of estimates of time and effort. Expenses related to information technology, fundraising, events, meetings and conferences, grants and fellowships, survey and research are charged to the appropriate program as they are incurred. The allocation method of expenses for the year ended June 30, 2018 was modified to conform to the method used for the year ended June 30, 2019, in accordance with the new guidance provided by Accounting Standards Update (ASU) 2016-14.

#### Donated Services and Materials

Contributions of services are recognized if the services received create or enhance non-financial assets or require special skills, and are provided by individuals possessing those skills and would typically need to be purchased if not provided by donation. Contributed services and promises to give services that do not meet the above criteria are not recognized. During 2019 and 2018, the Foundation received \$47,077 and \$48,116, respectively, in donated materials or services, primarily legal fees.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

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

#### **Donated Services and Materials** (continued)

In addition, the Foundation has estimated that total volunteer time donated during the years ended June 30, 2019 and 2018 was worth approximately \$325,000 and \$309,000, respectively, valued at \$25.43 and \$24.69 per hour, respectively. These services are not recorded in the accompanying financial statements as they did not meet the requirements as noted in the previous paragraph.

#### Income Taxes

The Foundation has received a favorable tax determination letter from the Internal Revenue Service stating that it is exempt from the payment of income taxes on its exempt activities under Section 501(c)(3) of the Internal Revenue Code. However, the Foundation is subject to unrelated business income tax for activities conducted outside its tax-exempt purpose. During 2019 and 2018, the Foundation did not conduct unrelated business activities.

Accordingly, no provision for income taxes is reflected in the accompanying financial statements.

The Foundation has no uncertain tax positions that qualify for either recognition or disclosure in the financial statements and no interest and penalties have been recorded in the accompanying financial statements related to uncertain tax positions.

The Foundation files an informational income tax return for Federal reporting purposes. The Foundation is not currently under audit by any income tax jurisdictions.

#### Reclassifications

Certain items in the June 30, 2018 financial statements have been reclassified to conform to the June 30, 2019 financial statement presentation. The reclassifications had no impact on previously reported net assets.

#### **Recent Accounting Pronouncements**

#### ASU 2014-09

In May 2014, the FASB issued ASU 2014-09, *Revenue from Contracts with Customers*. The standard's core principle is that an entity will recognize revenue when it transfers promised goods or services to customers in an amount that reflects the consideration to which the entity expects to be entitled in exchange for those goods or services. This standard also includes expanded disclosure requirements that result in an entity providing users of the financial statements with comprehensive information about the nature, amount, timing, and uncertainty of revenue and cash flows arising from the entity's contracts with customers. ASU 2014-09 is effective for non-public entities for fiscal years beginning after December 15, 2018, with early adoption permitted for fiscal years beginning after December 15, 2016. The Foundation is currently in the process of evaluating the impact of adoption of this ASU on the financial statements.

#### ASU 2016-02

In February 2016, the FASB issued ASU 2016-02, *Leases (Topic 842)*. The guidance in ASU 2016-02 supersedes the lease recognition requirements in ASC Topic 840, *Leases* (FAS 13). ASU 2016-02 requires an entity to recognize assets and liabilities on the balance sheet for the rights and obligations created by leased assets and provide additional disclosures. ASU 2016-02 is effective for non-public entities for fiscal years beginning after December 15, 2020, with early adoption permitted. The Foundation is currently in the process of evaluating the impact of adoption of this ASU on the financial statements.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

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

#### Change in Accounting Principle

The Foundation adopted ASU 2016-14, *Presentation of Financial Statements of Not-for-Profit Entities*, effective July 1, 2018. The update addresses the complexity and understandability of net asset classification, deficiencies in information about liquidity and availability of resources, and the lack of consistency in the type of information provided about expenses and investment return. This ASU has been applied retrospectively to all periods presented.

#### **Subsequent Events**

The date to which events occurring after June 30, 2019, the date of the most recent statement of financial position, have been evaluated for possible adjustment to the financial statements or disclosure is March 4, 2020, which is the date on which the financial statements were available to be issued.

#### 3. LIQUIDITY AND AVAILABILITY

Financial assets available within one year of the statement of financial position date for general expenditure, such as operating expenses, are as follows at June 30, 2019:

					A۱	ailable to	
			Una	available for	Μ	eet Cash	
		Gross		General	Needs With		
Description of Financial Asset	Amount		E	Expenditure		One Year	
Cash and cash equivalents	\$	147,831	\$	-	\$	147,831	
Contributions receivable, net		161,286		(60,167)		101,119	
Contracts receivable		2,763		-		2,763	
Investments		1,348,450		(653,641)		694,809	
Total financial assets available							
within one year	\$	1,660,330	\$	(713,808)	\$	946,522	

Financial assets subject to donor restrictions that make them unavailable for general expenditure within one year of the financial position date were \$713,808 at June 30, 2019. Financial assets subject to Board designations were \$782,895 at June 30, 2019. Although the Foundation does not intend to spend from the Board-designated net assets (other than amounts appropriated for general expenditure as part of the Board's annual budget approval and appropriation), these amounts could be made available if necessary.

The Foundation has a goal to maintain financial assets, which consist of cash and cash equivalents, on hand to meet three months of budgeted operating expenses.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 4. INVESTMENTS

Investment income included in the statements of activities and changes in net assets is as follows:

	2019			2018
Interest and dividends	\$	42,952		\$ 42,137
Net realized and unrealized gain on investments		54,608		80,310
Investment income, net	\$	97,560		\$ 122,447

External and direct internal investment expenses of \$11,254 and \$12,975 at June 30, 2019 and 2018, respectively, are netted against realized and unrealized gains.

#### 5. FAIR VALUE MEASUREMENTS

Financial stock

Industrial stock

Healthcare stock

Technology stock

Subtotals

Municipal bonds

Corporate bonds

Totals

The following tables summarize the Foundation's financial assets that were measured at fair value on a recurring basis as of June 30:

	2019							
		Level 1		Level 2	Le	evel 3		Total
Common stocks								
Consumer stock	\$	214,907	\$	-	\$	-	\$	214,907
Energy stock		47,599		-		-		47,599
Financial stock		108,594		-		-		108,594
Healthcare stock		199,154		-		-		199,154
Industrial stock		104,840		-		-		104,840
Technology stock		141,606		-		-		141,606
Subtotals		816,700		-		-		816,700
Municipal bonds		-		126,319		-		126,319
Corporate bonds		-		405,431		-		405,431
Totals	\$	816,700	\$	531,750	\$	-	\$	1,348,450
	2018							
		Level 1		Level 2	Le	evel 3		Total
Common stocks								
Consumer stock	\$	234,734	\$	-	\$	-	\$	234,734
Energy stock		75,576		-		-		75,576

124,920

233,833

153,221

194,835

1,017,119

249,067

154,755

\$ 1,420,941

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We evaluated the significance of transfers between the levels based upon the nature of the financial
instrument and size of the transfer relative to the total investments. For the years ended June 30,
2019 and 2018, there were no transfers in or out of Levels 1, 2 or 3.

\$

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249,067

154,755

403,822

\$

124,920

233,833

153,221

194,835

-

-

1,017,119

\$ 1,017,119

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

### 6. CONTRIBUTIONS RECEIVABLE

Contributions receivable consist of the following at June 30:

	2019	2018			
Contributions due in less than one year	\$ 161,286	\$ 187,584			
Less: Allowance for uncollectible contributions	-	(3,339)			
Net current contributions receivable	161,286	184,245			
Due in one to five years	-	15,000			
Less: Discount at present value	-	(1,016)			
Net long-term contributions receivable	-	13,984			
Total contributions receivable	\$ 161,286	\$ 198,229			

#### 7. LINE OF CREDIT

In July 2012, the Foundation entered into a \$100,000 line of credit agreement with a commercial bank. The line is renewed annually each July, and currently expires in July 2020. Outstanding borrowings on the line of credit bear interest at the Wall Street Journal Prime rate. There was no outstanding balance on the line of credit as of June 30, 2019 and 2018.

#### 8. NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions consist of the following at June 30:

	2019		 2018	
Subject to expenditure for specified purpose				
Research	\$	502,946	\$ 751,894	
Conferences		15,776	122,592	
Education and support		131,788	105,748	
Events		8,810	 9,532	
Total		659,320	989,766	
Subject to the passage of time		15,500	15,500	
Perpetual in nature		38,988	 38,988	
Total net assets with donor restrictions	\$	713,808	\$ 1,044,254	

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 9. NET ASSETS RELEASED FROM DONOR RESTRICTIONS

Net assets released from donor restrictions by incurring expenses satisfying the restricted purposes, or by occurrence of other events specified by donors, is as follows at June 30:

	2019			2018	
Purpose restriction					
Research	\$	512,440	\$	362,507	
Conferences		157,949		55,147	
Education and support		89,220		119,680	
Events		18,907		6,271	
Total		778,516	_	543,605	
Time restriction					
Operations		-		15,500	
Total net assets released from donor restrictions	\$	778,516	\$	559,105	

#### 10. COMMITMENTS

In December 2014, the Foundation renewed its existing office space lease. The lease agreement provides for initial monthly payments of \$6,187 with an annual escalation increase at a rate of two percent, expiring on November 30, 2020. The lease also requires that the Foundation pay their pro-rata share of any building operating expenses in excess of the agreed-upon amount. Rent expense for the years ended June 30, 2019 and 2018 was \$78,919 and \$76,992, respectively.

The Foundation has entered into several agreements for office equipment and support services.

Future minimum payments under all lease agreements are as follows as of June 30, 2019:

<u>Year ending June 30</u> :	
2020	\$ 85,082
2021	35,514
2022	1,186
Total future payments	\$ 121,782

The Foundation has entered into an agreement with a human resources leasing group to provide all related human resource services for employees. The agreement is on a month-to-month basis and may be cancelled by the Foundation with 30 days written notice.

In 2017, the Foundation entered into a strategic alliance with the Canadian Osteogenesis Imperfecta Society (COIS) to provide verified medical information and access to support networks to people living with OI and their families who reside in Canada for a small administrative fee. This agreement is set to expire on June 30, 2020, with an extension option. Donations collected on behalf of the COIS are included in related party payable at June 30, 2018. There was no COIS donations on hand at June 30, 2019.

# NOTES TO FINANCIAL STATEMENTS JUNE 30, 2019 AND 2018

#### 11. CONCENTRATION OF RISK

For the year ended June 30, 2019, two entities accounted for 78 percent of contributions receivable. For the year ended June 30, 2018, two entities accounted for 45 percent of contributions receivable and one entity accounted for 100 percent of grants receivable.

#### 12. RETIREMENT PLAN

The Foundation sponsors a 401(k) retirement plan that covers all eligible employees. The Foundation matches the first 4 percent of employee contributions. Contributions to the plan totaled \$25,278 and \$24,682 for the years ended June 30, 2019 and 2018, respectively.

#### 13. RISKS AND UNCERTAINTIES

The Foundation invests in various investment securities. Investment securities are exposed to various risks such as interest rate, market and credit risks. Due to the level of risk associated with certain investment securities, it is at least reasonably possible that changes in the values of investment securities will occur in the near term and such changes could materially affect the Foundation's investments and the amounts reported in the statements of financial position and the statements of activities and changes in net assets.