



## FINANCIAL REPORT

**OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

YEARS ENDED JUNE 30, 2018 AND 2017

# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

## **FINANCIAL REPORT YEARS ENDED JUNE 30, 2018 AND 2017**

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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, 2018 and 2017, and the related statements of activities and changes in net assets 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, 2018 and 2017, 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.

## Report on Supplementary Information

Our audits were conducted for the purpose of forming an opinion on the financial statements as a whole. The supplemental schedules of expenses by services are presented for purposes of additional analysis and are not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audits of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the financial statements as a whole.

A handwritten signature in black ink, reading "Thompson Greenspan". The signature is written in a cursive, flowing style.

Fairfax, Virginia  
April 9, 2019

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## STATEMENTS OF FINANCIAL POSITION JUNE 30, 2018 AND 2017

	<u>2018</u>	<u>2017</u>
<b>ASSETS</b>		
<b>Current Assets</b>		
Cash and cash equivalents	\$ 388,988	\$ 120,836
Contributions receivable, net	184,245	234,810
Grants receivable	168,000	168,000
Investments	1,420,941	1,630,533
Inventory	16,811	17,373
Prepaid expenses	<u>49,398</u>	<u>34,722</u>
Total Current Assets	<u>2,228,383</u>	<u>2,206,274</u>
<b>Fixed Assets</b>		
Furniture and equipment	134,451	178,126
Accumulated depreciation	<u>(111,605)</u>	<u>(149,171)</u>
Net Fixed Assets	<u>22,846</u>	<u>28,955</u>
<b>Other Assets</b>		
Long-term contributions receivable, net	13,984	54,477
Beneficial interest in assets held in perpetual trust	15,500	15,500
Deposits	<u>6,762</u>	<u>6,762</u>
Total Other Assets	<u>36,246</u>	<u>76,739</u>
<b>Total Assets</b>	<u><u>\$ 2,287,475</u></u>	<u><u>\$ 2,311,968</u></u>

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

	<u>2018</u>	<u>2017</u>
<b>LIABILITIES AND NET ASSETS</b>		
<b>Current Liabilities</b>		
Accounts payable	\$ 51,575	\$ 62,829
Accrued payroll liabilities	23,860	27,890
Related party payable	15,256	-
Deferred revenue	117,805	12,850
Promises to give to others	<u>239,500</u>	<u>324,404</u>
<b>Total Current Liabilities</b>	<u>447,996</u>	<u>427,973</u>
<b>Net Assets</b>		
Unrestricted net assets	795,225	997,443
Temporarily restricted net assets	1,005,266	832,064
Permanently restricted net assets	<u>38,988</u>	<u>54,488</u>
<b>Total Net Assets</b>	<u>1,839,479</u>	<u>1,883,995</u>
 <b>Total Liabilities and Net Assets</b>	 <u><u>\$ 2,287,475</u></u>	 <u><u>\$ 2,311,968</u></u>

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS YEARS ENDED JUNE 30, 2018 AND 2017

	2018				2017			
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
<b>Support and Revenue</b>								
Contributions and grants	\$ 167,726	\$ 548,959	\$ -	\$ 716,685	\$ 160,193	\$ 532,266	\$ -	\$ 692,459
Event revenue	575,563	33,827	-	609,390	634,063	110,983	-	745,046
Investment income	135,422	-	-	135,422	181,760	-	-	181,760
Direct mailing revenue	243,631	-	-	243,631	240,251	-	-	240,251
Conference revenue	-	134,021	-	134,021	121,533	6,565	-	128,098
Product sales, less cost of goods sold of \$562 for 2018 and \$1,039 for 2017	1,710	-	-	1,710	1,700	-	-	1,700
In-kind contributions	48,116	-	-	48,116	57,343	-	-	57,343
Net assets released from restrictions	559,105	(543,605)	(15,500)	-	516,080	(516,080)	-	-
<b>Total Support and Revenue</b>	<b>1,731,273</b>	<b>173,202</b>	<b>(15,500)</b>	<b>1,888,975</b>	<b>1,912,923</b>	<b>133,734</b>	<b>-</b>	<b>2,046,657</b>
<b>Expenses</b>								
Program services								
Research	560,563	-	-	560,563	703,445	-	-	703,445
Education and support	508,453	-	-	508,453	504,883	-	-	504,883
Conferences	102,614	-	-	102,614	359,723	-	-	359,723
Public awareness	87,736	-	-	87,736	53,090	-	-	53,090
<b>Total Program Services</b>	<b>1,259,366</b>	<b>-</b>	<b>-</b>	<b>1,259,366</b>	<b>1,621,141</b>	<b>-</b>	<b>-</b>	<b>1,621,141</b>
Support services								
General and administration	144,857	-	-	144,857	105,582	-	-	105,582
Fundraising	529,268	-	-	529,268	471,678	-	-	471,678
<b>Total Support Services</b>	<b>674,125</b>	<b>-</b>	<b>-</b>	<b>674,125</b>	<b>577,260</b>	<b>-</b>	<b>-</b>	<b>577,260</b>
<b>Total Expenses</b>	<b>1,933,491</b>	<b>-</b>	<b>-</b>	<b>1,933,491</b>	<b>2,198,401</b>	<b>-</b>	<b>-</b>	<b>2,198,401</b>
<b>Change in Net Assets</b>	<b>(202,218)</b>	<b>173,202</b>	<b>(15,500)</b>	<b>(44,516)</b>	<b>(285,478)</b>	<b>133,734</b>	<b>-</b>	<b>(151,744)</b>
<b>Net Assets, beginning of year</b>	<b>997,443</b>	<b>832,064</b>	<b>54,488</b>	<b>1,883,995</b>	<b>1,282,921</b>	<b>698,330</b>	<b>54,488</b>	<b>2,035,739</b>
<b>Net Assets, end of year</b>	<b>\$ 795,225</b>	<b>\$ 1,005,266</b>	<b>\$ 38,988</b>	<b>\$ 1,839,479</b>	<b>\$ 997,443</b>	<b>\$ 832,064</b>	<b>\$ 54,488</b>	<b>\$ 1,883,995</b>

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

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## STATEMENTS OF CASH FLOWS YEARS ENDED JUNE 30, 2018 AND 2017

	<u>2018</u>	<u>2017</u>
<b>Cash Flows from Operating Activities</b>		
Change in net assets	\$ (44,516)	\$ (151,744)
Adjustments to reconcile change in net assets to net cash used by operating activities		
Depreciation	11,401	11,558
Unrealized loss (gain) on investments	69,355	(45,878)
Realized gain on investments	(162,640)	(98,073)
(Increase) Decrease in		
Contributions receivable, net	91,058	9,597
Inventory	562	(760)
Prepaid expenses	(14,676)	4,999
Increase (Decrease) in		
Accounts payable and accruals	(15,284)	(12,045)
Deferred revenue	104,955	(127,491)
Promises to give to others	(84,904)	114,192
	<u>(44,689)</u>	<u>(295,645)</u>
<b>Net Cash Used by Operating Activities</b>		
<b>Cash Flows from Investing Activities</b>		
Payments for the purchase of property	(5,292)	(11,113)
Payments for the purchase of investments	(249,437)	(186,627)
Proceeds from sale of investments	552,314	376,339
	<u>297,585</u>	<u>178,599</u>
<b>Net Cash Provided by Investing Activities</b>		
<b>Cash Flows from Financing Activities</b>		
Collections on behalf of and payable to related party	15,256	-
	<u>268,152</u>	<u>(117,046)</u>
<b>Net Increase (Decrease) in Cash and Cash Equivalents</b>		
<b>Cash and Cash Equivalents, beginning of year</b>	<u>120,836</u>	<u>237,882</u>
<b>Cash and Cash Equivalents, end of year</b>	<u><u>\$ 388,988</u></u>	<u><u>\$ 120,836</u></u>

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



# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

## **NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017**

### **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 second year funding to Dr. Ivan Duran Jimenez from UCLA and his work on new mechanisms and therapies for OI caused by mutations in type I procollagen chaperones.

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 Institute 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 five 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, and Cologne Hospital in Cologne, Germany. 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](http://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 (18 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 2,300 times and are a very popular feature of OIF's medical professional educational outreach.

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

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

#### Research (continued)

Scientific Meetings – OIF gathered more than one hundred scientists and researchers for the 17th Annual OIF Science Meeting on April 18-20, 2018. Dr. Christina Jacobsen and Dr. Matthew Warman of Children's Hospital in Boston chaired the meeting, titled "Outcome Measures and Endpoints to Advance Therapeutic Options in Patients with OI." Presentations explored topics such as Measuring Efficacy of Physical Rehabilitation in Children and Adults and Craniofacial and Oral Health Outcome Measures, which included a patient panel to discuss patient perspectives on outcome measures. There was also an update from Dr. Brendan Lee on the work of the BBDC. 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.

A clinical meeting on OI was hosted by OIF Medical Advisory Council members Dr. Jay Shapiro and Dr. Cathleen Raggio on October 5-7, 2017 in Baltimore, Maryland. The meeting was for clinicians and medical professionals who directly manage the care of children and adults living with OI, which was developed as part of the Jamie Kendall Fund for OI Adult Health. Sessions covered the clinical perspective of topics such as growth impairment, dental disease, pulmonary function, cardiac disease, rehabilitation and function, orthopedic treatment, pharmacologic treatment, quality of life issues and more.

OIF successfully co-sponsored the Rare Bone Disease Working Group meeting at the American Society of Bone and Mineral Research (ASBMR) annual meeting in September 2017. This year's meeting, chaired by Dr. Matthew Drake of the Mayo Clinic, began with an update on the BBDC by Principal Investigator, Dr. Brendan Lee of Baylor College of Medicine. Later on in the meeting, OIF Medical Advisory Council Chairman Dr. Francis Glorieux presented on the topic "30 Years of Treatment of OI: Where We Are and Where We Are Going." Presentations throughout the meeting discussed cutting-edge research on bone pain and the biology of sclerostin and its role in bone health.

OI Adult Health Initiative – In fiscal year 2018, OIF funded the first year of a new 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.

Impact Grant Program – 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 31 families' (72 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.

# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

## **NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017**

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

#### **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.

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 800 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 2018, the Foundation held one regional conference in Portland, Oregon (November 2017), drawing more than 100 attendees.

# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

## **NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017**

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

#### **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, 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 2018 was May 5-12. 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 2018, OIF reached more than 175,000 people on Facebook and gained 120 new Facebook followers.

OIF manages four social networking sites and continues to offer, through its website [www.oif.org](http://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 more than 10,830 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.

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

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

#### **Cash and Cash Equivalents (continued)**

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, 2018 and 2017, the Foundation received \$7,829 and \$6,363, respectively, in donated stock that was immediately converted into cash and recognized as cash from operating activities in the accompanying statements of cash flows.

#### **Inventory**

Inventory is recorded at the lower of cost or market using the first-in, first-out (FIFO) method of inventory valuation. Inventory consists of books and videos to help children cope with OI, as well as small goods to promote OI awareness.

#### **Prepaid Expenses**

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

#### **Contributions Receivable**

Contributions receivable represents 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). The AFR was 2.86 percent and 1.96 percent at June 30, 2018 and 2017, respectively.

#### **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, 2018 and 2017 was \$11,401 and \$11,558, 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:

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

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

#### **Fair Value (continued)**

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.

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, 2018 and 2017.

*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.

#### **Promises to Give to Others**

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

Promises to give in future years are recorded as unrestricted support because it is believed that the intent of the donor is to support the Foundation's operations in the years the promises are made.

#### **Deferred Revenue**

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

# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

## **NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017**

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

#### **Net Assets**

Net assets are reported by the Foundation in accordance with generally accepted accounting principles. Accordingly, net assets have been reported using the following categories.

##### **Unrestricted**

Unrestricted net assets represent resources over which the Board of Directors has discretionary control, and are used to carry out operations of the Foundation in accordance with their by-laws. Unrestricted net assets have been reserved by the Board of Directors for future operations. For the years ended June 30, 2018 and 2017, the balance of the Board-designated net assets was \$795,225 and \$997,443, respectively.

##### **Temporarily Restricted**

Temporarily restricted net assets represent contributions and grants which have been restricted by donors for specific programs or activities. Restrictions which have been met by the passage of time or expenditure of net assets are reported as net assets released from restrictions on the statements of activities and changes in net assets. Temporarily restricted funds received and utilized in the same operating period are reported as temporarily restricted revenue and net assets released from restrictions on the statements of activities and changes in net assets. For the years ended June 30, 2018 and 2017, the Foundation received \$716,807 and \$649,814, respectively, in temporarily restricted assets. As of June 30, 2018 and 2017, temporarily restricted net assets were \$1,005,266 and \$832,064, respectively.

##### **Permanently Restricted**

Permanently restricted net assets represent contributions which have been restricted by donors indefinitely. The permanently restricted net assets have been identified by the Foundation and consist of an Endowment Fund. For the years ended June 30, 2018 and 2017, the Foundation did not receive any permanently restricted contributions. As of June 30, 2018 and 2017, permanently restricted net assets were \$38,988 and \$54,488, respectively.

#### **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 awarded 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.

#### **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 costs of providing the various programs and other activities have been summarized on a functional basis in the statements of activities and changes in net assets. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

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

#### **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 2018 and 2017, the Foundation received \$48,116 and \$57,343, respectively, in donated materials or services, primarily legal fees.

In addition, the Foundation has estimated that total volunteer time donated during the years ended June 30, 2018 and 2017 was worth approximately \$308,500 and \$296,000, respectively, valued at approximately \$24.69 and \$24.14 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 2018 and 2017, 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.

#### **Recent Accounting Pronouncements**

##### **ASU 2014-09**

In May 2014, the FASB issued Accounting Standards Update (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.



# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

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

#### Recent Accounting Pronouncements (continued)

##### 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, 2019, with early adoption permitted. The Foundation is currently in the process of evaluating the impact of adoption of this ASU on the financial statements.

##### ASU 2016-14

In August 2016, the FASB issued ASU 2016-14, *Presentation of Financial Statements of Not-for-Profit Entities*. ASU 2016-14 eliminates the distinction between resources with permanent restrictions and those with temporary restrictions from the face of not-for-profit financial statements by reducing the current three net asset classes (unrestricted, temporarily restricted, and permanently restricted) to two classes (net assets with donor restrictions and net assets without donor restrictions). ASU 2016-14 also requires enhanced disclosures regarding board designations, the method(s) used to allocate costs among program and support functions, underwater endowment funds, and qualitative and quantitative information that communicates how the organization will meet cash needs for general expenditures within one year of the balance sheet date. ASU 2016-14 is effective for not-for-profit entities for fiscal periods beginning after December 15, 2017 and for interim periods within fiscal years beginning after December 15, 2018, with retrospective application to all periods presented. Early application of the amendments is permitted. The amendments should be initially adopted only for an annual fiscal period or for the first interim period within the fiscal year of adoption. The Foundation is currently in the process of evaluating the impact of adoption of this ASU on the financial statements.

#### Reclassification

Certain items in the June 30, 2017 financial statements have been reclassified to conform to the June 30, 2018 financial statement presentation.

#### Subsequent Events

The date to which events occurring after June 30, 2018, the date of the most recent statement of financial position, have been evaluated for possible adjustment to the financial statements or disclosure is April 9, 2019, which is the date on which the financial statements were available to be issued.

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

### 3. INVESTMENTS

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

	2018	2017
Interest and dividends	\$ 42,137	\$ 37,809
Net realized and unrealized gain on investments	93,285	143,951
Investment income, net	<u>\$ 135,422</u>	<u>\$ 181,760</u>

Investment and custodial fees netted against realized and unrealized gains were \$12,975 and \$12,933 at June 30, 2018 and 2017, respectively.

### 4. FAIR VALUE MEASUREMENTS

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

	2018		
	Level 1	Level 2	Level 3
Common stocks			
Consumer stock	\$ 234,734	\$ -	\$ -
Energy stock	75,576	-	-
Financial stock	124,920	-	-
Healthcare stock	233,833	-	-
Industrial stock	153,221	-	-
Technology stock	194,835	-	-
Subtotals	1,017,119	-	-
Municipal bonds	-	249,067	-
Corporate bonds	-	154,755	-
Totals	<u>\$ 1,017,119</u>	<u>\$ 403,822</u>	<u>\$ -</u>

	2017		
	Level 1	Level 2	Level 3
Common stocks			
Consumer stock	\$ 240,311	\$ -	\$ -
Energy stock	73,748	-	-
Financial stock	139,321	-	-
Healthcare stock	240,380	-	-
Industrial stock	204,242	-	-
Technology stock	229,088	-	-
Subtotals	1,127,090	-	-
Municipal bonds	-	163,110	-
Corporate bonds	-	340,333	-
Totals	<u>\$ 1,127,090</u>	<u>\$ 503,443</u>	<u>\$ -</u>

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 ending June 30, 2018 and 2017, there were no transfers in or out of Levels 1, 2 or 3.

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

### 5. CONTRIBUTIONS RECEIVABLE

Contributions receivable consist of the following at June 30:

	2018	2017
Contributions due in less than one year	\$ 184,245	\$ 238,149
Less: Allowance for uncollectible contributions	-	(3,339)
Net current contributions receivable	<u>184,245</u>	<u>234,810</u>
Due in one to five years	15,000	57,500
Less: Discount at present value	(1,016)	(3,023)
Net long-term contributions receivable	<u>13,984</u>	<u>54,477</u>
Total contributions receivable	<u>\$ 198,229</u>	<u>\$ 289,287</u>

### 6. 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 2019. 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, 2018 and 2017.

### 7. TEMPORARILY RESTRICTED NET ASSETS

Temporarily restricted net assets consist of the following at June 30:

	2018	2017
BBDC	\$ 268,929	\$ 293,000
Adult Health	277,852	243,934
Research	205,113	151,284
Biennial Conference	122,592	11,441
Impact Grant Program	93,198	105,602
Buynak Fund to Benefit Operations	15,500	-
Regional Meeting	9,532	14,253
Services to Benefit Hearing Impaired	7,550	7,550
Resource Center	5,000	5,000
Total temporarily restricted net assets	<u>\$ 1,005,266</u>	<u>\$ 832,064</u>

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

## NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017

### 7. TEMPORARILY RESTRICTED NET ASSETS (continued)

Temporarily restricted net assets are available for the following purposes at June 30:

	2018	2017
Research	\$ 751,894	\$ 688,218
Education and support	105,748	118,152
Conferences	122,592	11,441
Events	9,532	14,253
Total purpose-restricted net assets	989,766	832,064
Operations		
Total time-restricted net assets	15,500	-
Total temporarily restricted net assets	<u>\$ 1,005,266</u>	<u>\$ 832,064</u>

### 8. 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, 2018 and 2017 was \$76,992 and \$75,106, 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, 2018:

<u>Year ending June 30:</u>	
2019	\$ 84,305
2020	85,082
2021	35,514
2022	1,186
Total future payments	<u>\$ 206,087</u>

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 year-end.

### 9. CONCENTRATION OF RISK

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. For the year ended June 30, 2017, two entities accounted for 70 percent of contributions receivable and one entity accounted for 100 percent of grants receivable.

# **OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

## **NOTES TO FINANCIAL STATEMENTS JUNE 30, 2018 AND 2017**

### **10. 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 \$24,682 and \$24,817 for the years ended June 30, 2018 and 2017, respectively.

### **11. 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.

## **SUPPLEMENTARY INFORMATION**

**OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

**SCHEDULE OF EXPENSES BY SERVICES  
YEAR ENDED JUNE 30, 2018**

	Program Services					Support Services			Overall Total
	Conferences	Education and Support	Research	Public Awareness	Total	General and Administration	Fundraising	Total	
Salaries and fringe benefits	\$ 71,805	\$ 221,815	\$ 104,730	\$ 58,365	\$ 456,715	\$ 264,815	\$ 140,349	\$ 405,164	\$ 861,879
Bank fees	-	-	67	-	67	31,824	-	31,824	31,891
Consulting fees	-	-	22,190	-	22,190	-	-	-	22,190
Depreciation	-	-	-	-	-	11,401	-	11,401	11,401
Dues and subscriptions	-	2,494	-	-	2,494	-	-	-	2,494
Equipment rental and maintenance	-	-	-	-	-	807	2,827	3,634	3,634
Event expense	-	-	-	-	-	-	211,027	211,027	211,027
Grants and fellowships	-	107,484	180,936	-	288,420	-	-	-	288,420
Information technology and web support	37	37,046	2,030	-	39,113	19,180	3,541	22,721	61,834
Insurance	-	-	-	-	-	3,506	2,148	5,654	5,654
Interest expense	-	-	-	-	-	6,476	-	6,476	6,476
Licenses and permits	-	-	-	-	-	-	8,236	8,236	8,236
Meetings and conferences	6,273	12,599	122,645	-	141,517	8,712	103	8,815	150,332
Bad debt expense	-	-	-	-	-	7,500	-	7,500	7,500
Occupancy	-	-	-	-	-	76,992	-	76,992	76,992
Office supplies	-	526	-	-	526	17,395	551	17,946	18,472
Postage and delivery	-	4,082	413	-	4,495	2,184	12,943	15,127	19,622
Printing and duplicating	-	11,731	4,103	-	15,834	2,563	2,490	5,053	20,887
Professional fees	-	-	-	-	-	38,919	3,046	41,965	41,965
Survey	-	-	2,286	-	2,286	-	-	-	2,286
Telephone	63	95	577	17	752	8,267	1,084	9,351	10,103
Travel	45	1,316	123	-	1,484	1,223	19,373	20,596	22,080
In-kind expenses	2,340	-	-	10,500	12,840	27,463	7,813	35,276	48,116
<b>Total expenses, before indirect cost allocation</b>	<b>80,563</b>	<b>399,188</b>	<b>440,100</b>	<b>68,882</b>	<b>988,733</b>	<b>529,227</b>	<b>415,531</b>	<b>944,758</b>	<b>1,933,491</b>
<b>Indirect cost allocation</b>	<b>22,051</b>	<b>109,265</b>	<b>120,463</b>	<b>18,854</b>	<b>270,633</b>	<b>(384,370)</b>	<b>113,737</b>	<b>(270,633)</b>	<b>-</b>
<b>Total Expenses</b>	<b>\$ 102,614</b>	<b>\$ 508,453</b>	<b>\$ 560,563</b>	<b>\$ 87,736</b>	<b>\$ 1,259,366</b>	<b>\$ 144,857</b>	<b>\$ 529,268</b>	<b>\$ 674,125</b>	<b>\$ 1,933,491</b>

**OSTEOGENESIS IMPERFECTA FOUNDATION, INC.**

**SCHEDULE OF EXPENSES BY SERVICES  
YEAR ENDED JUNE 30, 2017**

	Program Services					Support Services			Overall Total
	Conferences	Education and Support	Research	Public Awareness	Total	General and Administration	Fundraising	Total	
Salaries and fringe benefits	\$ 87,723	\$ 254,477	\$ 108,451	\$ 43,547	\$ 494,198	\$ 222,344	\$ 152,074	\$ 374,418	\$ 868,616
Bank fees	8	-	-	-	8	30,119	-	30,119	30,127
Consulting fees	-	-	14,091	-	14,091	-	500	500	14,591
Depreciation	-	-	-	-	-	11,558	-	11,558	11,558
Dues and subscriptions	-	2,895	-	-	2,895	-	320	320	3,215
Equipment rental and maintenance	-	-	181	-	181	1,190	2,120	3,310	3,491
Event expense	192,483	-	-	-	192,483	-	185,610	185,610	378,093
Grants and fellowships	-	80,031	341,992	-	422,023	-	-	-	422,023
Information technology and web support	-	37,469	2,265	-	39,734	20,443	2,040	22,483	62,217
Insurance	-	-	-	-	-	3,607	1,963	5,570	5,570
Interest expense	-	-	-	-	-	4,888	-	4,888	4,888
Licenses and permits	-	-	-	-	-	-	4,535	4,535	4,535
Meetings and conferences	12,170	13,338	91,467	-	116,975	2,829	59	2,888	119,863
Occupancy	-	-	-	-	-	75,106	-	75,106	75,106
Office supplies	1,042	317	91	-	1,450	15,928	1,082	17,010	18,460
Postage and delivery	464	4,042	100	-	4,606	2,512	6,804	9,316	13,922
Printing and duplicating	-	9,077	70	-	9,147	2,410	3,159	5,569	14,716
Professional fees	-	-	-	-	-	38,762	854	39,616	39,616
Survey	-	-	10,582	-	10,582	-	-	-	10,582
Telephone	34	114	308	-	456	8,360	184	8,544	9,000
Travel	-	6,567	1,398	-	7,965	5,149	17,755	22,904	30,869
In-kind expenses	1,136	5,800	6,000	-	12,936	36,575	7,832	44,407	57,343
Total expenses, before indirect cost allocation	295,060	414,127	576,996	43,547	1,329,730	481,780	386,891	868,671	2,198,401
Indirect cost allocation	64,663	90,756	126,449	9,543	291,411	(376,198)	84,787	(291,411)	-
Total Expenses	<u>\$ 359,723</u>	<u>\$ 504,883</u>	<u>\$ 703,445</u>	<u>\$ 53,090</u>	<u>\$ 1,621,141</u>	<u>\$ 105,582</u>	<u>\$ 471,678</u>	<u>\$ 577,260</u>	<u>\$ 2,198,401</u>