## **EISNERAMPER**

### THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND THE FTD DISORDERS REGISTRY LLC

CONSOLIDATED FINANCIAL STATEMENTS

JUNE 30, 2021 (with consolidating supplementary information)

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EisnerAmper LLP One Logan Square 130 North 18<sup>th</sup> Street, Suite 3000 Philadelphia, PA 19103 T 215.881.8800 F 215.881.8801 www.eisneramper.com

### **INDEPENDENT AUDITORS' REPORT**

To the Board of Directors of The Association for Frontotemporal Degeneration and The FTD Disorders Registry LLC

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

We have audited the accompanying consolidated financial statements of The Association for Frontotemporal Degeneration (a nonprofit organization) and The FTD Disorders Registry LLC (a nonprofit organization) (collectively, the "Organization"), which comprise the consolidated statement of financial position as of June 30, 2021, and the related consolidated statements of activities, changes in net assets, functional expenses and cash flows for the year then ended, and the related notes to the consolidated financial statements.

### Management's Responsibility for the Consolidated Financial Statements

Management is responsible for the preparation and fair presentation of these consolidated 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 consolidated financial statements that are free from material misstatement, whether due to fraud or error.

### Auditor's Responsibility

Our responsibility is to express an opinion on these consolidated financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the consolidated financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

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### Opinion

In our opinion, the consolidated financial statements referred to on the previous page present fairly, in all material respects, the consolidated financial position of The Association for Frontotemporal Degeneration and The FTD Disorders Registry LLC as of June 30, 2021, and the consolidated changes in their net assets and their cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

### Other Matter

Our audits were conducted for the purpose of forming an opinion on the consolidated financial statements as a whole. The accompanying supplementary information shown on pages 21 and 23 is presented for purposes of additional analysis and is not a required part of the consolidated 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 consolidated financial statements. The information has been subject to the auditing procedures applied to the audits of the consolidated financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the consolidated financial statements or to the consolidated 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 consolidated financial statements as a whole.

Eisner Amper LLP

EISNERAMPER LLP Philadelphia, Pennsylvania October 14, 2021

## Consolidated Statement of Financial Position June 30, 2021

### ASSETS

Current assets:	
Cash and cash equivalents	\$ 1,233,928
Pledges receivable	2,317,407
Governmental grants receivable	41,891
Investments	35,715,893
Prepaid expenses	62,540
Total current assets	39,371,659
Pledges receivable, net of current portion and discount	6,445,080
Software and equipment, net of accumulated depreciation of \$186,890	71,233
Security deposit	26,063
	\$ 45,914,035
LIABILITIES	
Current liabilities:	
Accounts payable and accrued expenses	\$ 283,828
Deferred revenues	75,934
Research grants payable	780,217
Total current liabilities	1,139,979
Research grants payable	715,979
Deferred rent	80,429
Total liabilities	1,936,387
NET ASSETS	
Net assets without donor restrictions:	
Undesignated	28,345,755
Board-designated	6,329,870
Noncontrolling interest	546,103
	35,221,728
Net assets with donor restrictions	8,755,920
Total net assets	43,977,648
	\$ 45,914,035

### Consolidated Statement of Activities Year Ended June 30, 2021

	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total
Revenue and support:			
Contributions	\$24,403,999	\$ 2,296,085	\$ 26,700,084
Government grants	83,851	-	83,851
Investment / interest and other income	1,485,563	-	1,485,563
Special event revenue	1,531,438	-	1,531,438
Net assets released from restrictions	4,222,874	(4,222,874)	
	31,727,725	(1,926,789)	29,800,936
Expenses:			
Program services:	1 000 070		4 000 070
Awareness and advocacy	1,082,279	-	1,082,279 1,185,356
Education and support Research	1,185,356 4,020,912	-	4,020,912
FTD Registry	611,097	-	611,097
1 1D Registry	011,001		011,007
Total program services	6,899,644		6,899,644
Supporting services:			
Management and general	530,720	-	530,720
Fundraising	831,236		831,236
Total supporting services	1,361,956		1,361,956
	8,261,600	<u> </u>	8,261,600
Other income:			
Gain on forgiveness of PPP loan	355,100	<u> </u>	355,100
Change in net assets	23,821,225	(1,926,789)	21,894,436
Change in net assets attributable to the noncontrolling interest	(32,080)		(32,080)
Change in net assets attributable to the controlling interest	\$23,853,305	\$ (1,926,789)	\$ 21,862,356

### Consolidated Statement of Changes in Net Assets Year Ended June 30, 2021

	Controllin	g Interest	Noncontrolling Interest in	
	Net Assets Without Donor	Net Assets With Donor	Net Assets Without Donor	
	Restrictions	Restrictions	Restrictions	Total
Net assets at July 1, 2020	\$ 10,822,320	\$10,682,709	\$ 578,183	\$ 22,083,212
Change in net assets	23,853,305	(1,926,789)	(32,080)	21,894,436
Net assets at June 30, 2021	\$34,675,625	\$ 8,755,920	\$ 546,103	\$ 43,977,648

Consolidated Statement of Functional Expenses Year Ended June 30, 2021

		Pi	rogram Services	5		Su	pporting Service	es	
	Awareness	Education				Management			
	and	and		FTD		and			
	Advocacy	Support	Research	Registry	Subtotal	General	Fundraising	Subtotal	Total
Expenses:									
Salaries and wages	\$ 572,729	\$ 591,646	\$ 393,412	\$ 265,051	\$1,822,838	\$ 209,103	\$ 451,351	\$ 660,454	\$ 2,483,292
Payroll taxes	42,132	43,935	28,529	20,126	134,722	12,408	33,128	45,536	180,258
Employee benefits	73,663	77,948	49,395	44,339	245,345	24,225	59,668	83,893	329,238
Advertising	112,860	-	-	471	113,331	-	-	-	113,331
Bank and credit card									
processing fees	-	103	306	-	409	1,506	29,605	31,111	31,520
Bad debts	-	-	-	-	-	-	2,185	2,185	2,185
Conferences and meetings	18,900	38,259	121,918	-	179,077	199	-	199	179,276
Depreciation	2,429	3,036	1,822	40,481	47,768	2,430	2,429	4,859	52,627
Dues and subscriptions	2,510	3,447	3,766	-	9,723	1,040	6,250	7,290	17,013
Education - training	3,252	3,077	997	-	7,326	996	3,528	4,524	11,850
Events	894	-	-	-	894	-	71,779	71,779	72,673
Grants awarded	-	102,954	3,243,022	-	3,345,976	-	-	-	3,345,976
Insurance	3,693	6,462	2,770	-	12,925	8,844	2,770	11,614	24,539
Management Information									
Systems	91,164	100,811	58,962	239,398	490,335	39,191	50,339	89,530	579,865
Office and supplies	4,345	21,475	6,183	1,231	33,234	36,296	4,638	40,934	74,168
Postage and shipping	7,138	7,738	1,213	-	16,089	1,429	12,722	14,151	30,240
Printing and copying	24,094	3,004	-	-	27,098	1,387	26,318	27,705	54,803
Professional fees	76,586	102,771	75,556	-	254,913	148,177	42,564	190,741	445,654
Rent	40,175	70,305	30,131	-	140,611	53,000	30,131	83,131	223,742
Telecommunications									
and data	5,225	8,323	1,862	-	15,410	1,831	1,831	3,662	19,072
Travel	490	62	1,068		1,620	200		200	1,820
Total expenses	\$ 1,082,279	\$ 1,185,356	\$4,020,912	\$ 611,097	\$6,899,644	\$ 542,262	\$ 831,236	\$ 1,373,498	\$ 8,273,142

### Consolidated Statement of Cash Flows

Year Ended June 30, 2021

<b>Cash flows from operating activities:</b> Change in net assets Adjustments to reconcile change in net assets to net cash	\$ 21,894,436
provided by operating activities:	
Depreciation	52,627
Gain on forgiveness of PPP loan	(355,100)
Amortization of discount on contributions receivable	(122,404)
Donated securities	(2,087,608)
Proceeds from sale of donated securities	2,090,868
Realized and unrealized gain on investments	(1,177,771)
(Increase) decrease in assets:	
Accounts receivable	171
Pledges receivable	2,254,807
Governmental grants receivable	(649)
Prepaid expenses	(18,532)
Increase (decrease) in liabilities:	
Accounts payable and accrued expenses	174,014
Deferred revenues	(564,066)
Research grants payable	(335,558)
Deferred rent	761
Net cash provided by operating activities	21,805,996
Cash flows from investing activities:	
Proceeds from sale of investments	4,770,113
Purchase of investments	(34,127,612)
Net cash used in investing activities	(29,357,499)
Net decrease in cash and cash equivalents	(7,551,503)
Cash and cash equivalents at beginning of year	8,785,431
Cash and cash equivalents at end of year	\$ 1,233,928

### Notes to Consolidated Financial Statements June 30, 2021

### **NOTE A - NATURE OF ACTIVITIES**

The Association for Frontotemporal Degeneration ("AFTD") is a nonprofit corporation incorporated under the laws of the Commonwealth of Pennsylvania in November 2002.

Frontotemporal Degeneration ("FTD") is the most common cause of dementia for people under 60 in the United States. Despite that fact, today, FTD is still far too little known and poorly understood. Currently incurable and without approved treatments, FTD has profound effects on the lives of all it touches. It strikes at the heart of how individuals express themselves and relate to others, bringing a gradual, progressive decline in behavior, language and/or movement.

In response, the Organization dedicates itself to bringing help for individuals and families affected, and hope for a world with compassionate care, effective support and a future free of FTD.

With a community of volunteers, donors, advocates and professionals, the Organization works every day to advance FTD research, awareness, support for those directly impacted and education for health professionals, while advocating for appropriate, affordable services.

AFTD's research team works with leading and emerging FTD scientists to identify promising areas of research that will one day lead to effective treatments and a cure. AFTD provides support for people diagnosed in the form of grants, practical information and the comfort that comes in talking to someone who understands FTD, and AFTD works to educate health care professionals to provide appropriate care for this unique disease. AFTD also works to spread awareness of a disease that is still too little known, and to advocate for higher-quality care for families who find themselves with FTD in their lives.

The Organization's major source of support is contributions.

In September 2020, AFTD became the managing member of The FTD Disorders Registry LLC (the "Registry") with the responsibilities for oversight of all the Registry's day-to-day activities. The Registry was formed as a Delaware Limited Liability Company in 2015 by two founding members: (1) the Association for Frontotemporal Degeneration ("AFTD"), and (2) The Bluefield Project to Cure Frontotemporal Dementia ("Bluefield"). The Registry obtained exempt status from the Internal Revenue Service and therefore operates as a 501(c)(3) nonprofit organization for the sole purpose of creating and supporting the Registry's goals. The original funding for the Registry was provided by the founding members and by a contribution from the Rainwater Charitable Foundation ("Rainwater").

The Registry is governed by a Limited Liability Company Agreement which was amended and restated as of September 10, 2020 ("LLC Agreement") which defines the roles and responsibilities of the members and management of the Registry. From inception through September 9, 2020, the LLC Agreement stipulated that the Registry's day-to-day activities were to be managed by a management committee consisting of appointees of Bluefield, AFTD and Rainwater.

During 2019, AFTD and Bluefield, each owning a fifty percent (50%) membership interest in the Registry, collectively transferred and delivered a thirty-three and three-tenths percent (33.3%) membership interest in the Registry to Rainwater.

On June 12, 2020, Rainwater transferred the 33.3% interest in the Registry back to AFTD and Bluefield. As a result, AFTD and Bluefield each have a fifty percent (50%) membership interest in the Registry as of June 30, 2021.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE A - NATURE OF ACTIVITIES (CONTINUED)

The mission of the Registry is to facilitate and advance research into the spectrum of FTD disorders and to accelerate the development of treatments.

A diagnosis of FTD is an isolating event, and the Registry aims first and foremost to be a community resource where patients and families can appreciate their place within the broader FTD disorders community. The Registry intends to have the capacity to enroll both national and international participants and become a truly global resource supporting research and development efforts. The Registry will be a comprehensive and secure resource for information from respondents on key demographic, care-based, and disorder-specific information.

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

### [1] Principles of consolidation:

The accompanying consolidated financial statements include the accounts of The Association for Frontotemporal Degeneration and The FTD Disorders Registry LLC (collectively, the "Organization"). All intercompany accounts and transactions have been eliminated in consolidation. Noncontrolling interest includes 50% of the net assets and changes in net assets of FTD Disorders Registry as of Jun 30, 2021 since this interest is not directly controlled by AFTD.

### [2] Basis of accounting:

The accompanying consolidated financial statements have been prepared on the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America ("U.S. GAAP").

### [3] Classification of net assets:

Resources in the consolidated financial statements are classified for accounting and reporting purposes in classes of net assets according to the existence or absence of donor-imposed restrictions. The accompanying consolidated financial statements may include the following classes of net assets:

*Net Assets Without Donor Restrictions* - Net assets without donor restrictions are used to account for funds which have not been restricted by donors and over which the Board of Directors has discretionary control. In May 2010, the Board voted to create an operating reserve fund. The reserve balance is reviewed and updated annually. Board-designated reserve fund balance as of June 30, 2021 was \$1,329,870. In December 2017, the Board voted to create the David Geffen Investment Fund in order to sustain long-term funding. Board-designated David Geffen Investment Fund balance was \$5,000,000 as of June 30, 2021.

*Net Assets With Donor Restrictions* - Net assets subject to donor-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.

### [3] Use of estimates:

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

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

### [4] Cash and cash equivalents:

The Organization considers all cash and highly liquid investments with original maturities of three months or less when purchased to be cash equivalents.

### [5] Concentration of credit and market risk:

The Organization maintains its cash and cash equivalents in amounts which, at times, may exceed federally insured limits. The Organization has not experienced any losses in such accounts, and management believes that the Organization is not exposed to any significant risk of loss on these accounts.

### [6] Investments:

Investments consist primarily of assets invested in certificate of deposits, common stock, bonds, treasury bills and exchange-traded funds. All investments are stated at fair value. Unrealized and realized gains and losses are reflected in the accompanying consolidated statement of activities and changes in net assets. Investments received as gifts are recorded at fair value at the time of the donation and sold as soon as possible.

The Organization's investment securities are subject 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 those securities could occur in the near term and that such changes could materially affect the amounts reported in the accompanying consolidated financial statements.

The extent of the impact of the coronavirus (COVID-19) outbreak on the financial performance of the Organization's investments will depend on future developments, including the duration and spread of the outbreak and related advisories and restrictions and the impact of COVID-19 on the financial markets and the overall economy, all of which are highly uncertain and cannot be predicted. If the financial markets and/or the overall economy are impacted for an extended period, the Organization's investment results may be materially adversely affected.

### [7] Functional allocation of expenses:

Directly identifiable expenses are charged to program services, management and general, and fundraising. Salaries, payroll taxes and benefits are charged to the different functions based on the employee's actual functions performed. Expenses related to more than one function including management information systems, office and supplies, professional fees, travel, insurance, depreciation, postage and shipping, printing and copying, rent, dues and subscriptions and telecommunication and data are allocated based on usage or time and effort as estimated by management.

### [8] Federal tax status:

The Internal Revenue Service has classified the Organization as exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

### [8] Federal tax status: (continued)

Accounting for uncertainty in income taxes clarifies the accounting for uncertainty in income taxes recognized in an enterprise's financial statements. Management has analyzed the tax positions taken by the Organization, and has concluded that as of June 30, 2021, there are no uncertain tax positions taken or expected to be taken that would require recognition of a liability or disclosure in the consolidated financial statements. The Organization recognizes accrued interest and penalties associated with uncertain tax positions, if any. There were no income tax related interest or penalties recorded for the year ended June 30, 2021.

### [9] Prepaid expenses:

Prepaid expenses represent expenditures related to insurance, conferences and fundraising events conducted in the subsequent year.

### [10] Grants payable:

Conditional grants and promises to give are not recorded as expenses until the condition on which they depend have been met. A grants is deemed to be conditional if it includes one or more measureable barriers and a right of return or forfeiture.

The Organization records grants payable when the grants are approved which is when the Organization considers the grant awards to be unconditionally promised. As of June 30, 2021, there were no grant awards awaiting approval.

### [11] Software and equipment and depreciation:

Software and equipment are stated at cost or, if donated, at the estimated fair value at the date of donation less accumulated depreciation. AFTD capitalizes all costs in excess of \$2,500 and the Registry capitalizes all costs in excess of \$5,000. Depreciation of software and equipment is provided for on the straight-line method over the estimated useful lives of the assets ranging from three to five years. Depreciation for the year ended June 30, 2021 was \$52,627.

### [12] Paycheck Protection Program:

There are two acceptable methods for accounting for Paycheck Protection Program ("PPP") proceeds received under the Coronavirus Aid, Relief, and Economic Security Act ("CARES" Act). Entities can elect to treat the PPP proceeds received as a loan or as a conditional contribution. The Organization has elected to account for the PPP proceeds as a loan payable. Loan forgiveness will be recognized when the conditions for loan forgiveness are met and the forgiveness amount is formally approved by the bank and the U.S. Small Business Administration ("SBA").

In April 2020 and May 2020, the Organization received \$330,500 and \$54,600 in loans, respectively, pursuant to the CARES Act PPP. Neither principle nor interest was due for a six-month deferral period through October 2020 and November 2020, respectively, at which time monthly payments of principal and interest would commence. All unpaid principal and interest would be due at maturity in April 2022 and May 2022. The loan and all accrued interest was forgiven in full on April 20, 2021 and March 23, 2021 and is included as gain on extinguishment of PPP loan on the consolidated statements of activities and changes in net assets.

Notes to Consolidated Financial Statements June 30, 2021

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

### [13] Revenue recognition:

#### Contributions

Funding for the Organization's activities is achieved almost entirely through foundation, corporate and other support, contributions, and in-kind contributions, including unconditional promises to give. These donations provide funding to be used to support the mission of the Organization. As the donors are not receiving a benefit as a result of these transactions, the donations are considered to be contributions to the Organization. Some contributions require that funds be expended for a specific purpose, and are considered to be net assets with donor restrictions.

The Organization recognizes unconditional contributions when cash, securities or other assets or an unconditional promise to give is received, and are recorded after discounting to the present value of the expected future cash flows. Conditional promises to give - that is, those with a measurable performance or other barrier and a right of return - are not recognized until the conditions on which they depend have been met.

#### Governmental grants

The Organization receives government grants and contracts. These grants and contracts provide funding to be used for purposes indicated in the grant agreements. As the government is not receiving a benefit as a result of these transactions, the grants and contracts are considered to be contributions to the Organization. The grant and contract agreements contain spending requirements. As these stipulations create a barrier that must be achieved, government grants and contracts are considered to be conditional contributions until such time as the barriers are overcome. Contributions from these grant and contract agreements are therefore recognized as revenue when costs are incurred and specific service requirements are met, as required by the agreements. There were no conditional government grants as of June 30, 2021 that will be recognized in subsequent years as costs are incurred and service requirements are met.

Until the financial information required by the funding sources is accepted, costs billed for program services under cost reimbursement contracts are subject to review and possible disallowance. In management's opinion, the potential for material disallowances is remote and, therefore, is not a barrier that would prevent the recognition of revenue.

### Special Events

In May 2014, Financial Accounting Standards Board ("FASB") issued Accounting Standards Codification ("ASC") 606, *Revenue from Contracts with Customers*, which provided a five-step analysis of contracts to determine when and how revenue is recognized and replaced most existing revenue recognition guidance in U.S. GAAP. The core principle of the new guidance is that an entity should recognize revenue to reflect the transfer of goods and services to customers in an amount equal to the consideration the entity received or expects to receive. ASC 606 is effective for annual reporting periods beginning after December 15, 2019. The Organization adopted ASC 606 with a date of initial application of July 1, 2020.

The Organization adopted ASC 606 using the modified retrospective method, recognizing the cumulative effect of initially applying the new guidance as an adjustment to the opening net assets balance as of July 1, 2020.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

### [14] Revenue Recognition: (continued)

### Special Events (continued)

As part of the adoption of ASC 606, the Organization elected to use the following transition practical expedients: (1) all contract modifications that occurred prior to the date of initial application when identifying the satisfied and unsatisfied performance obligations, determining the transaction price, and allocating the transaction price have been reflected in the aggregate; and (2) ASC 606 was applied only to contracts that were not completed at the initial date of adoption. Because contract modifications are minimal, there is not a significant impact as a result of electing these practical expedients. There were no significant changes that resulted from adoption and, therefore, there was no adjustment to the net assets balance on the date of adoption. The Organization does not expect the adoption of the new revenue standard to have a material impact on its consolidated statement of activities and changes in net assets on an ongoing basis.

The Organization earns revenue from contracts with customers through special events.

For periods commencing on July 1, 2020, fee-for-service revenue related to special events is recognized when or as the performance obligations in each contract are satisfied for the amount of consideration the Organization expects to be entitled to receive for the related service.

The Organization records special events revenue equal to contribution revenue less the cost of direct benefits to donors which is included in special events revenue on the consolidated statement of activities and changes in net assets. The recognition of revenue is conditional on the event taking place, as this is the point in time when the performance obligation of hosting the event occurs, and attendees can no longer request a refund for their ticket purchases. The amounts are collected at the time of ticket purchase and are included in deferred revenue until recognized. As of June 30, 2021, there were conditional contributions associated with special events of \$75,934 which is included in deferred revenue on the consolidated statement of financial position.

### [15] Contributed services:

Donated services are recognized as contributions if the services (a) create or enhance nonfinancial assets or (b) require specialized skills, are performed by people with those skills and would otherwise be purchased by the Organization. Contributed services are measured at the cost recognized by such entity based on time spent by the entity's personnel in providing those services and included in salaries and wages and professional fees on the consolidated statement of functional expenses. The Organization also received contributed use of a space. The value of the donated space and utilities is included in the consolidated statement of functional expenses with rent.

	Program Services	Management and General	Fundraising	Total
Salaries Legal Rent	\$ - 40,128 	\$ 25,110 8,567 1,339	\$ - 8,567 	\$ 25,110 57,262 1,339
	\$ 40,128	\$ 35,016	\$ 8,567	\$ 83,711

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

### [16] Upcoming accounting pronouncements:

In February 2016, FASB issued Accounting Standards Update ("ASU") 2016-02, *Leases (Topic 842)*. The ASU's core principle is to increase transparency and comparability among organizations by recognizing lease assets and liabilities on the consolidated statement of financial position and disclosing key information. ASU 2016-02 will be effective for fiscal years beginning after December 15, 2021, with early adoption permitted. The Organization's lease commitment is through 2031 and management is currently evaluating the effect that this new guidance will have on its consolidated financial statements and related disclosures.

In September 2020, FASB issued ASU 2020-07 (Topic 958), *Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets*. The ASU requires nonprofits to change their financial statement presentation and disclosure of contributed nonfinancial assets, or gifts-in-kind. Under the new standard's requirements, gifts-in-kind are to be presented as a separate line item, instead of remaining grouped among contributions of cash or other financial assets, on the consolidated statement of activities and changes in net assets. The ASU requires the new standard to be applied retrospectively, with amendments taking effect for annual reporting periods beginning after December 15, 2021. The ASU does allow for early adoption. Management is currently evaluating the effect that this new guidance will have on its consolidated financial statements and related disclosures.

### NOTE C - LIQUIDITY AND AVAILABILITY

Financial assets available for general expenditure, that is, without donor or other restrictions limiting their use, within one year of the consolidated statement of financial position date, comprise the following as of June 30, 2021:

Current financial assets:	
Cash and cash equivalents	\$ 1,233,928
Accounts receivable	1,517
Pledges receivable	2,317,407
Governmental grants receivable	41,891
Investments	35,715,893
Total current financial assets at year-end	39,310,636
Less amounts not available to be used within one year:	
Net assets with donor restrictions subject to expenditures	
for specified purposes	(1,800,000)
Board-designated for specific purpose	(6,329,870)
	(8,129,870)
Financial assets available to meet cash needs for	
general expenditures within one year	\$ 31,180,766

General expenditures include program services expenses, management and general expenses, and fundraising expenses expected to be paid in the subsequent year.

As part of the Organization's liquidity management plan, the Organization structures its financial assets to be available as its general expenditures, liabilities and other obligations come due. In addition, the Organization invests cash in excess of daily requirements in short-term investments.

#### **Notes to Consolidated Financial Statements** June 30, 2021

### **NOTE D - CASH AND CASH EQUIVALENTS**

Cash and cash equivalents include all funds in banks (checking and savings). The components of cash and cash equivalents as of June 30, 2021 are as follows:

Checking accounts Savings accounts	\$	664,124 569,804
	<u>۴</u>	1 000 000
	\$	1,233,928

Savings accounts earn interest at a rate of 0.01% per annum as of June 30, 2021. The Organization attempts to limit its credit risk associated with cash equivalents by utilizing highly-rated financial institutions.

### **NOTE E - INVESTMENTS**

Investments consist of the following as of June 30, 2021:

Investments:	
Common stock	\$ 5,032,022
Fixed income ETFs	11,526,882
Corporate bonds	1,193,454
Municipal bonds	140,003
Treasury bonds	3,055,059
Mutual funds	5,000,000
Investments measured at fair value	25,947,420
Certificate of deposit	2,000,000
Money market funds	7,768,473
Total investments	\$ 35,715,893

### **NOTE F - FAIR VALUE MEASUREMENTS**

FASB ASC 820, Fair Value Measurements and Disclosures, provides the framework for measuring fair value. The framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value, and defines fair value as the price that would be received to sell an asset or paid to transfer a liability (i.e., the "exit price") in an orderly transaction between market participants.

The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets (Level 1 measurements), and the lowest priority to unobservable inputs (Level 3 measurements). The three levels of the fair value hierarchy are described as follows:

Level 1 - Inputs to the valuation methodology are unadjusted guoted prices for identical assets or liabilities in active markets.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE F - FAIR VALUE MEASUREMENTS (CONTINUED)

Level 2 - Inputs to the valuation methodology include (a) quoted prices for similar assets or liabilities in active markets; (b) quoted prices for identical or similar assets or liabilities in inactive markets; (c) inputs other than quoted prices that are observable for the asset or liability; or (d) inputs that are derived principally from or corroborated by observable market data by correlation or other means.

Level 3 - Inputs to the valuation methodology are unobservable and significant to the fair value measurement. Assets utilizing Level 3 inputs are funds held in trust by others.

The financial instrument's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. The valuation levels are not necessarily an indication of the risk or liquidity associated with the underlying assets.

The following is a description of the valuation methodologies used for assets measured at fair value.

*Common stock, fixed income ETFs and mutual funds* - Valued at the closing market price on the stock exchange where it is traded.

Bonds - Valued at the present value of future cash flows.

The preceding methods described may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, although the Organization 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.

The following table sets forth, by level, the Organization's investment assets at fair value, within the aforementioned fair value hierarchy, as of June 30, 2021:

	Investment Assets at Fair Value as of June 30, 2021			
	Level 1	Level 2	Level 3	Total
Common stock	\$ 5,032,022	\$ -	\$-	\$ 5,032,022
Fixed income ETFs	11,526,882	-	-	11,526,882
Corporate bonds	-	1,193,454	-	1,193,454
Municipal bonds	-	140,003	-	140,003
Treasury bonds	-	3,055,059	-	3,055,059
Mutual funds	5,000,000			5,000,000
Total investment assets at fair value	\$ 21,558,904	\$ 4,388,516	<u>\$ -</u>	\$ 25,947,420

### Changes in fair value levels:

The availability of observable market data is monitored to assess the appropriate classification of financial instruments within the fair value hierarchy. Changes in economic conditions or model-based valuation techniques may require the transfer of financial instruments from one fair value level to another. In such instances, the transfer is reported at the beginning of the reporting period. For the year ended June 30, 2021, there were no transfers into or out of Levels 1, 2 or 3.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE G - GOVERNMENTAL GRANTS AND PLEDGES RECEIVABLE

Government grants and pledges receivable outstanding as of June 30, 2021 are summarized as follows:

	Governmental Grants Receivable	Pledges Receivable
Due within one year Due within one to five years	\$ 41,891 	\$ 2,317,407 6,800,000
Total receivables	41,891	9,117,407
Less total discounts to net present value		(354,920)
Total net receivables	\$ 41,891	\$ 8,762,487

The present value for contributions was calculated using discount factors ranging from 1.42% to 2.75%.

### NOTE H - CONDITIONAL PROMISES TO GIVE

During the year ended June 30, 2018, the Organization received a conditional commitment of \$10 million, in the form of a matching grant, for The David Geffen Fund at AFTD. The pledge, payable in \$1 million installments over a ten-year period, is contingent upon the receipt of the annual \$1 million installment of a \$10 million unconditional pledge, also payable over ten years, made during the year ended June 30, 2018. For the year ended June 30, 2021, the Organization recognized \$1 million of contribution revenue on this conditional commitment due to the receipt of annual installment of the original \$10 million pledge. In accordance with professional standards, the balance of \$6,000,000 was not recorded in the consolidated statement of financial position as of June 30, 2021 because the conditions for the commitment have not been met.

### NOTE I - RESEARCH GRANTS PAYABLE

Research grants payable as of June 30, 2021 are summarized as follows:

Research grants payable expected to be paid:		
Less than one year	\$	780,217
One to five years		715,979
	¢	4 400 400
Total research grants payable	\$	1,496,196

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE J - NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are restricted for the following purposes or period as of June 30, 2021:

Subject to passage of time:	
Promises to give that are not restricted by donors	\$ 5,779,972
Subject to expenditures for specified purpose:	
Research, FTD/ALS	
Research, other	1,551,567
Awareness	5,011
Promises to give, the proceeds from which	
have been restricted by donors for:	
Research, FTD Biomarkers	418,438
Research, FTD/ALS	1,000,932
	2,975,948
	\$ 8,755,920

Net assets were released from donor restriction by incurring expenses satisfying the restricted purpose specified by the donors as follows for the year ended June 30, 2021:

Satisfaction of time restriction: Funds received	\$ 1,181,889
Satisfaction of purpose restriction:	
Research, FTD Biomarkers	963,697
Research, Target ALS	1,305,181
Research, other	660,576
Awareness	7,369
Volunteer Program Expansion	 104,162
	\$ 4,222,874

### NOTE K - LEASE AGREEMENT

In August 2019, AFTD entered into an operating lease for new office space commencing on November 25, 2020 and expiring on May 31, 2027. In addition to monthly payments ranging from \$12,969 and \$15,390, AFTD is also required to pay monthly operating expenses of \$5,049. AFTD's rent for the first six months of the lease was abated. Since there was a rent abatement and there are rent escalations throughout the lease term, the lease will be recorded on a straight-line basis. The difference between the straight-line expense amount and the actual rent paid based on the terms of the lease agreement is recorded in deferred rent on the consolidated statement of financial position.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE K - LEASE AGREEMENT (CONTINUED)

Schedule future annual lease payments under all operating leases as of June 30, 2021 are as follows:

Year Ending June 30,	
2022	\$ 162,196
2023	166,346
2024	170,496
2025	174,646
2026	178,796
Thereafter	167,556
	\$ 1,020,036

Total rental expense for the year ended June 30, 2021 was \$220,507.

### NOTE L - CONTINGENT GRANT AWARDS

Respite and Travel Grants to caregivers. Recipients of Respite grants may use the funds on respite care, financial relief or other health-related services that best meet their needs. AFTD also offers Travel grants for people with FTD or their immediate family members to attend an FTD-related education event, including the annual AFTD Education Conference. The grants expire six months after the award date. As of June 30, 2021, there were \$24,964 of unexpired grants awarded for which the Organization has not received any reimbursement requests.

### NOTE M - SIMPLE IRA PLAN

The Organization has a SIMPLE IRA Plan available to all employees earning at least \$5,000 per year. Eligible employees are able to contribute up to 100% of their total compensation or \$13,500 for calendar year 2021, or \$16,500 if over age 50. The Organization must match 3% in at least three out of every five consecutive years. For the year ended June 30, 2021, the employer match was \$57,316.

### NOTE N - RELATED PARTY TRANSACTIONS

A Board member of AFTD is a substantial contributor for the year ended June 30, 2021. Contributions, including promises to give, from this contributor for the year ended June 30, 2021 were \$20,013,451. In addition, the Board member is an officer of a foundation that is a substantial contributor to AFTD. Contributions receivable from the Foundation were \$8,645,080 as of June 30, 2021.

A Board member of AFTD is a substantial contributor to the Organization. Donations for the year ended June 30, 2021 were \$2,032,143.

### Notes to Consolidated Financial Statements June 30, 2021

### NOTE N - RELATED PARTY TRANSACTIONS (CONTINUED)

The Bluefield Project to Cure Frontotemporal Dementia is a co-founder of the Registry and has a 50% Member interest in the FTD Registry, LLC. Rodney Pearlman is President of Bluefield and served as the Treasurer of the Registry and a member of the Management Committee until it was dissolved in September 2020. He serves as a voting member on the Registry's Board of Directors. The Registry received a \$150,000 in contributed income for the year ended June 30, 2021.

Dianna Wheaton, the Registry Director, has a personal relationship with a key contractor to the Registry. The contract is managed by the President of the Registry. Payments to the contractor totaled \$75,621 for the year ended June 30, 2021.

### **NOTE O - COMMITMENTS AND CONTINGENCIES**

In the normal course of business, there are various outstanding commitments and contingent liabilities, such as commitments to enter into contracts and future funding agreements, which are not reflected in the consolidated financial statements. Such commitments and contingencies also include risks associated with various economic and operating factors, which include (a) grant restrictions and donor conditions which obligate the Organization to fulfill certain requirements as set forth in grant instruments, (b) funding levels which vary based on factors beyond the Organization's control, such as generosity of donors and general economic conditions, (c) employment and service agreements with key management personnel, including executive officers of the organization, and (d) financial risks associated with funds on deposit in accounts at financial institutions. Certain of the grants and contracts (including current and prior costs) are subject to adjustment upon review and final acceptance by the granting agency. Management believes that such commitments, contingencies and risks will not have a material adverse effect on the consolidated financial statements.

The extent of the impact and effects of the COVID-19 outbreak on the operation and financial performance of the Organization's business are unknown. The impact will depend on future developments, including the duration and spread of the outbreak, related travel advisories and restrictions, the consequential staff shortages, or the uncertainty with respect to the accessibility of additional liquidity or capital markets, all of which are highly uncertain and cannot be predicted. However, the Organization does not expect that the outbreak will have a material adverse effect on its business or financial results at this time.

### NOTE P - SUBSEQUENT EVENTS

The Organization has evaluated subsequent events through October 14, 2021, which is the date the consolidated financial statements were available to be issued.

### Consolidating Schedule of Financial Position June 31, 2021

	The Association for Frontotemporal Degeneration	FTD Disorders Registry LLC	Eliminations	Consolidated Total
ASSETS				
Current assets: Cash and cash equivalents Accounts receivable Pledges receivable Governmental grants receivable Investments Prepaid expenses	\$ 195,085 1,517 2,317,407 - 35,715,893 47,744	\$ 1,038,843 - - 41,891 - 14,796	\$ - 1,517 - - - -	\$ 1,233,928 - 2,317,407 41,891 35,715,893 62,540
Total current assets	38,277,646	1,095,530	1,517	39,371,659
Pledges receivable, net of current portion and discount	6,445,080	-	-	6,445,080
Software and equipment, net of accumulated depreciation of \$186,890	37,499	33,734	-	71,233
Security deposit	26,063			26,063
LIABILITIES Current liabilities: Accounts payable and accrued expenses Deferred revenues Research grants payable	\$ 248,287 \$ 248,287 75,934 780,217	<u>\$ 1,129,264</u> \$ 37,058 - -	\$ 1,517 \$ 1,517 - -	\$ 283,828 75,934 780,217
Total current liabilities	1,104,438	37,058	1,517	1,139,979
Research grants payable Deferred rent	715,979 80,429	-	-	715,979 80,429
Total liabilities	1,900,846	37,058	1,517	1,936,387
NET ASSETS Net assets without donor restrictions: Undesignated Board-designated	27,799,652 6,329,870 34,129,522	1,092,206		28,891,858 6,329,870 35,221,728
Net assets with donor restrictions	8,755,920			8,755,920
Total net assets	42,885,442	1,092,206		43,977,648
	\$ 44,786,288	\$ 1,129,264	\$ 1,517	\$ 45,914,035

### Consolidating Schedule of Activities Year Ended June 30, 2021

	The Association for Frontotemporal Degeneration			FTD Disorders Registry LLC				Consolidated Totals		
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Eliminations	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Consolidated Total
Revenue and support:										
Contributions Government grants Investment / interest and	\$ 24,071,817 -	\$ 2,296,085 -	\$ 26,367,902 -	\$ 482,182 83,851	\$ - -	\$ 482,182 83,851	\$ 150,000 -	\$ 24,403,999 83,851	\$ 2,296,085 -	\$ 26,700,084 83,851
other income Special event revenue Net assets released from	1,431,114 1,531,438	-	1,431,114 1,531,438	65,991 -	-	65,991 -	11,542 -	1,485,563 1,531,438	-	1,485,563 1,531,438
restrictions	4,222,874	(4,222,874)	<u> </u>					4,222,874	(4,222,874)	
	31,257,243	(1,926,789)	29,330,454	632,024	<u> </u>	632,024	161,542	31,727,725	(1,926,789)	29,800,936
Expenses: Program services:										
Awareness and advocacy	1,082,279	-	1,082,279	-	-	-	-	1,082,279	-	1,082,279
Education and support	1,185,356	-	1,185,356	-	-	-	-	1,185,356	-	1,185,356
Research	4,170,912	-	4,170,912	-	-	-	150,000	4,020,912	-	4,020,912
The FTD Registry LLC				611,097		611,097		611,097		611,097
Total program services	6,438,547		6,438,547	611,097		611,097	150,000	6,899,644		6,899,644
Supporting services:										
Management and general	402,576	-	402,576	139,686	-	139,686	11,542	530,720	-	530,720
Fundraising	831,236		831,236					831,236		831,236
	1,233,812	<u> </u>	1,233,812	139,686		139,686	11,542	1,361,956		1,361,956
	7,672,359	<u> </u>	7,672,359	750,783		750,783	161,542	8,261,600		8,261,600
Other income: Gain on forgiveness of										
PPP loan	300,500	<u> </u>	300,500	54,600		54,600		355,100		355,100
Change in net assets	\$ 23,885,384	\$ (1,926,789)	\$ 21,958,595	\$ (64,159)	\$ -	\$ (64,159)	<u>\$ -</u>	\$ 23,821,225	\$ (1,926,789)	\$ 21,894,436

Schedule of Functional Expenses – The Association for Frontotemporal Degeneration Year Ended June 30, 2021

	The Association for Frontotemporal Degeneration								
	Program Services				Su				
	Awareness and	Education and			Management and				
	Advocacy	Support	Research	Subtotal	General	Fundraising	Subtotal	Total	
Expenses:									
Salaries and wages	\$ 572,729	\$ 591,646	\$ 393,412	\$ 1,557,787	\$ 136,536	\$ 451,351	\$ 587,887	\$ 2,145,674	
Payroll taxes	42,132	43,935	28,529	114,596	10,081	33,128	43,209	157,805	
Employee benefits	73,663	77,948	49,395	201,006	19,568	59,668	79,236	280,242	
Advertising	112,860	-	-	112,860	-	-	-	112,860	
Bank and credit card processing fees	-	103	306	409	906	29,605	30,511	30,920	
Bad Debts	-	-	-	-	-	2,185	2,185	2,185	
Conferences and meetings	18,900	38,259	121,918	179,077	199	-	199	179,276	
Depreciation	2,429	3,036	1,822	7,287	2,430	2,429	4,859	12,146	
Dues and subscriptions	2,510	3,447	3,766	9,723	1,040	6,250	7,290	17,013	
Education - training	3,252	3,077	997	7,326	996	3,528	4,524	11,850	
Events	894	-	-	894	-	71,779	71,779	72,673	
Grants awarded	-	102,954	3,393,022	3,495,976	-	-	-	3,495,976	
Insurance	3,693	6,462	2,770	12,925	4,342	2,770	7,112	20,037	
Management Information Systems	91,164	100,811	58,962	250,937	38,907	50,339	89,246	340,183	
Office and supplies	4,345	21,475	6,183	32,003	30,001	4,638	34,639	66,642	
Postage and shipping	7,138	7,738	1,213	16,089	1,429	12,722	14,151	30,240	
Printing and copying	24,094	3,004	-	27,098	1,387	26,318	27,705	54,803	
Professional fees	76,586	102,771	75,556	254,913	101,062	42,564	143,626	398,539	
Rent	40,175	70,305	30,131	140,611	51,661	30,131	81,792	222,403	
Telecommunications and data	5,225	8,323	1,862	15,410	1,831	1,831	3,662	19,072	
Travel	490	62	1,068	1,620	200		200	1,820	
Total expenses	\$ 1,082,279	\$ 1,185,356	\$4,170,912	\$ 6,438,547	\$ 402,576	\$ 831,236	\$ 1,233,812	\$ 7,672,359	