

EISNERAMPER

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

CONSOLIDATED FINANCIAL STATEMENTS

**JUNE 30, 2022 and 2021
(with consolidating supplementary information)**



THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

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INDEPENDENT AUDITORS' REPORT

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

Report on the Audit of the Financial Statements

Opinion

We have audited the consolidated financial statements of The Association for Frontotemporal Degeneration (a nonprofit organization) and FTD Disorders Registry LLC (a nonprofit organization) (collectively, the "Organization"), which comprise the consolidated statements of financial position as of June 30, 2022 and 2021, and the related consolidated statements of activities, changes in net assets, functional expenses, and cash flows for each of the years then ended, and the related notes to the consolidated financial statements.

In our opinion, the accompanying financial statements referred to above present fairly, in all material respects, the consolidated financial position of The Association for Frontotemporal Degeneration and FTD Disorders Registry LLC as of June 30, 2022 and 2021, and the changes in their net assets and their cash flows for each of the years then ended in accordance with accounting principles generally accepted in the United States of America

Basis for Opinion

We conducted our audits in accordance with auditing standards generally accepted in the United States of America ("GAAS"). Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Organization and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibility of Management 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about the Organization's ability to continue as a going concern for one year after the date that the financial statements are available to be issued.



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Auditors' Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 Organization's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Organization's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control-related matters that we identified during the audit.

Supplementary Information

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 23 to 30 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 financial statements. The information has been subject 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 GAAS. In our opinion, the supplementary information shown on pages 23 to 30 is fairly stated in all material respects in relation to the financial statements as a whole.



EISNERAMPER LLP
Philadelphia, Pennsylvania
December 14, 2022



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

Consolidated Statements of Financial Position

	June 30,	
	2022	2021
ASSETS		
Current assets:		
Cash and cash equivalents	\$ 1,161,722	\$ 1,233,928
Accounts receivable	726	-
Pledges receivable	2,677,367	2,317,407
Governmental grants receivable	61,248	41,891
Investments	36,665,426	35,715,893
Prepaid expenses	91,431	62,540
	40,657,920	39,371,659
 Pledges receivable, net of current portion and discount	 5,188,090	 6,445,080
 Software and equipment, net of accumulated depreciation of \$232,768 in 2022 and \$186,890 in 2021	 46,430	 71,233
 Security deposit	 26,063	 26,063
	\$ 45,918,503	\$ 45,914,035
LIABILITIES		
Current liabilities:		
Accounts payable and accrued expenses	\$ 360,084	283,828
Deferred revenues	30,538	75,934
Research grants payable	1,307,983	780,217
	1,698,605	1,139,979
 Research grants payable	 487,676	 715,979
Deferred rent	77,040	80,429
	2,263,321	1,936,387
 Commitments and contingencies		
NET ASSETS		
Net assets without donor restrictions:		
Undesignated	32,177,241	28,345,755
Board-designated	2,842,000	6,329,870
	35,019,241	34,675,625
 Net assets with donor restrictions	 8,093,137	 8,755,920
 Noncontrolling interest	 542,804	 546,103
	43,655,182	43,977,648
	\$ 45,918,503	\$ 45,914,035

See notes to consolidated financial statements

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

Consolidated Statements of Activities

	Year Ended June 30,					
	2022			2021		
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total
Revenue and support:						
Contributions	\$ 7,708,779	\$ 2,532,878	\$ 10,241,657	\$ 24,320,288	\$ 2,296,085	\$ 26,616,373
Government grants	220,600	-	220,600	83,851	-	83,851
Other income	4,537	-	4,537	67,731	-	67,731
Contributed services	113,493	-	113,493	57,262	-	57,262
Special event revenue, net of cost of direct benefits to donors of \$170,259 in 2022 and \$-0- in 2021	2,150,504	-	2,150,504	1,531,438	-	1,531,438
Net assets released from restrictions	3,153,161	(3,153,161)	-	4,222,874	(4,222,874)	-
	<u>13,351,074</u>	<u>(620,283)</u>	<u>12,730,791</u>	<u>30,283,444</u>	<u>(1,926,789)</u>	<u>28,356,655</u>
Expenses:						
Program services:						
Awareness and advocacy	1,589,047	-	1,589,047	1,082,279	-	1,082,279
Education and support	1,758,969	-	1,758,969	1,185,356	-	1,185,356
Research	3,675,017	-	3,675,017	4,020,912	-	4,020,912
FTD Registry	739,769	-	739,769	611,097	-	611,097
Total program services	<u>7,762,802</u>	<u>-</u>	<u>7,762,802</u>	<u>6,899,644</u>	<u>-</u>	<u>6,899,644</u>
Supporting services:						
Management and general	616,045	-	616,045	504,271	-	504,271
Fundraising	1,055,827	-	1,055,827	831,236	-	831,236
Total supporting services	<u>1,671,872</u>	<u>-</u>	<u>1,671,872</u>	<u>1,335,507</u>	<u>-</u>	<u>1,335,507</u>
	<u>9,434,674</u>	<u>-</u>	<u>9,434,674</u>	<u>8,235,151</u>	<u>-</u>	<u>8,235,151</u>
Change in net assets before other income (loss)	<u>3,916,400</u>	<u>(620,283)</u>	<u>3,296,117</u>	<u>22,048,293</u>	<u>(1,926,789)</u>	<u>20,121,504</u>
Other income (loss):						
Investment income (loss), net	(3,618,583)	-	(3,618,583)	1,417,832	-	1,417,832
Gain on forgiveness of PPP loan	-	-	-	355,100	-	355,100
Change in net assets	<u>297,817</u>	<u>(620,283)</u>	<u>(322,466)</u>	<u>23,821,225</u>	<u>(1,926,789)</u>	<u>21,894,436</u>
Change in net assets attributable to the noncontrolling interest	<u>(45,799)</u>	<u>42,500</u>	<u>(3,299)</u>	<u>(32,080)</u>	<u>-</u>	<u>(32,080)</u>
Change in net assets attributable to the controlling interest	<u>\$ 343,616</u>	<u>\$ (662,783)</u>	<u>\$ (319,167)</u>	<u>\$ 23,853,305</u>	<u>\$ (1,926,789)</u>	<u>\$ 21,926,516</u>

See notes to consolidated financial statements

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

**Consolidated Statements of Changes in Net Assets
Years Ended June 30, 2022 and 2021**

	Controlling Interest		Noncontrolling Interest		Total
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	
Net assets at July 1, 2020	\$ 10,822,320	\$ 10,682,709	\$ 578,183	\$ -	\$ 22,083,212
Change in net assets	<u>23,853,305</u>	<u>(1,926,789)</u>	<u>(32,080)</u>	<u>-</u>	<u>21,894,436</u>
Net assets at June 30, 2021	34,675,625	8,755,920	546,103	-	43,977,648
Change in net assets	<u>343,616</u>	<u>(662,783)</u>	<u>(45,799)</u>	<u>42,500</u>	<u>(322,466)</u>
Net assets at June 30, 2022	<u>\$ 35,019,241</u>	<u>\$ 8,093,137</u>	<u>\$ 500,304</u>	<u>\$ 42,500</u>	<u>\$ 43,655,182</u>

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

**Consolidated Statement of Functional Expenses
Year Ended June 30, 2022**

	Program Services					Supporting Services			Total
	Awareness and Advocacy	Education and Support	Research	FTD Registry	Subtotal	Management and General	Fundraising	Subtotal	
Expenses:									
Salaries and wages	\$ 609,376	\$ 851,165	\$ 736,285	\$ 387,671	\$ 2,584,497	\$ 143,929	\$ 513,952	\$ 657,881	\$ 3,242,378
Payroll taxes	45,669	63,379	54,936	27,036	191,020	14,943	38,722	53,665	244,685
Employee benefits	81,003	109,979	95,198	58,039	344,219	24,206	65,038	89,244	433,463
Advertising	127,360	-	-	2,480	129,840	10,293	-	10,293	140,133
Bank and credit card processing fees	37	393	155	583	1,168	811	40,269	41,080	42,248
Conferences and meetings - facilities and other costs	154,871	142,276	397,987	-	695,134	39,636	3	39,639	734,773
Depreciation	2,429	3,036	1,822	33,734	41,021	2,428	2,429	4,857	45,878
Dues and subscriptions	2,155	4,429	8,416	325	15,325	3,121	1,824	4,945	20,270
Education - training	5,070	8,863	3,855	-	17,788	5,815	14,161	19,976	37,764
Events - facilities and other costs	145,376	-	152	-	145,528	-	165,985	165,985	311,513
Grants awarded	-	201,892	2,084,254	-	2,286,146	-	-	-	2,286,146
Insurance	4,459	7,803	3,344	-	15,606	7,606	3,344	10,950	26,556
Management Information Systems	169,889	176,667	91,202	198,386	636,144	63,967	110,155	174,122	810,266
Office and supplies	10,274	4,790	1,777	-	16,841	75,367	1,717	77,084	93,925
Postage and shipping	16,659	5,326	1,107	-	23,092	3,136	7,650	10,786	33,878
Printing and copying	63,072	3,727	40	-	66,839	446	10,122	10,568	77,407
Professional fees	99,133	71,742	148,680	25,584	345,139	171,417	41,623	213,040	558,179
Rent	45,640	79,870	34,230	-	159,740	36,717	34,230	70,947	230,687
Telecommunications and data	5,596	22,923	2,466	-	30,985	10,085	2,637	12,722	43,707
Travel	979	709	9,111	5,931	16,730	2,122	1,966	4,088	20,818
Total expenses included in the expense section on the statements of activities and changes in net assets	1,589,047	1,758,969	3,675,017	739,769	7,762,802	616,045	1,055,827	1,671,872	9,434,674
Plus expenses included with revenue on the statements of activities and changes in net assets									
Cost of direct benefits to donors: Food and beverage	-	-	-	-	-	-	170,259	170,259	170,259
Total expenses	\$ 1,589,047	\$ 1,758,969	\$ 3,675,017	\$ 739,769	\$ 7,762,802	\$ 616,045	\$ 1,226,086	\$ 1,842,131	\$ 9,604,933

See notes to consolidated financial statements

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

**Consolidated Statement of Functional Expenses
Year Ended June 30, 2021**

	Program Services					Supporting Services			
	Awareness and Advocacy	Education and Support	Research	FTD Registry	Subtotal	Management and General	Fundraising	Subtotal	Total
Expenses:									
Salaries and wages	\$ 572,729	\$ 591,646	\$ 393,412	\$ 265,051	\$ 1,822,838	\$ 174,237	\$ 451,351	\$ 625,588	\$ 2,448,426
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	1,234	29,605	30,839	31,248
Bad debts	-	-	-	-	-	-	2,185	2,185	2,185
Conferences and meetings - facilities and other costs	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 - facilities and other costs	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	34,782	4,638	39,420	72,654
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	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	\$ 4,020,912	\$ 611,097	\$ 6,899,644	\$ 504,271	\$ 831,236	\$ 1,335,507	\$ 8,235,151

See notes to consolidated financial statements

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

Consolidated Statements of Cash Flows

	Year Ended June 30,	
	2022	2021
Cash flows from operating activities:		
Change in net assets	\$ (322,466)	\$ 21,894,436
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation	45,878	52,627
Gain on forgiveness of PPP loan	-	(355,100)
Amortization of discount on contributions receivable	(109,677)	(122,404)
Donated securities	(3,052,077)	(2,087,608)
Proceeds from sale of donated securities	2,968,193	2,090,868
Realized and unrealized (gain) loss on investments	3,950,531	(1,177,771)
(Increase) decrease in assets:		
Accounts receivable	(726)	171
Pledges receivable	1,006,707	2,254,807
Governmental grants receivable	(19,357)	(649)
Prepaid expenses	(28,891)	(18,532)
Increase (decrease) in liabilities:		
Accounts payable and accrued expenses	76,256	174,014
Deferred revenues	(45,396)	(564,066)
Research grants payable	299,463	(335,558)
Deferred rent	(3,389)	761
Net cash provided by operating activities	<u>4,765,049</u>	<u>21,805,996</u>
Cash flows from investing activities:		
Proceeds from sale of investments	21,721,364	4,770,113
Purchase of investments	(26,537,544)	(34,127,612)
Purchase of equipment	(21,075)	-
Net cash used in investing activities	<u>(4,837,255)</u>	<u>(29,357,499)</u>
Net decrease in cash and cash equivalents	(72,206)	(7,551,503)
Cash and cash equivalents at beginning of year	<u>1,233,928</u>	<u>8,785,431</u>
Cash and cash equivalents at end of year	\$ <u>1,161,722</u>	\$ <u>1,233,928</u>

See notes to consolidated financial statements

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 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, AFTD 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, AFTD works every day to advance FTD research, awareness and support for those directly impacted and education for health professionals, while advocating for appropriate and 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.

AFTD’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, 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.

AFTD and Bluefield each have a fifty percent (50%) membership interest in the Registry.

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.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

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 LLC as of both June 30, 2022 and 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") as applicable to not-for-profit organizations.

[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 (the "Board") has discretionary control. As of June 30, 2021, the Board-designated David Geffen Investment Fund balance was \$5,000,000 and the Board-designated operating reserve fund balance was \$1,329,870. In December 2021 and January 2022, respectively, the Board voted to consolidate the David Geffen Investment Fund and the operating reserve fund into an existing investment account and to dissolve the Board-designated funds. In January 2022, the AFTD Board voted to create two new designated funds. A Board-designated FTDDR Fund to support the expansion and management of the Registry was created. The balance of this fund as of June 30, 2022 was \$2,350,000. In addition, a Board-designated CEO Discretionary fund was created to provide the CEO with a pool of discretionary funds, available to them to invest in the mission and/or operations of AFTD. The balance of this fund as of June 30, 2022 was \$492,000.

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.

[4] 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.

[5] 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.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[6] Concentration of credit and market risk:

The Organization maintains its cash and cash equivalents in accounts 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.

[7] 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. Investment income (loss) consists of interest, dividends, realized and unrealized gains and losses, net of investment expenses. Unrealized gains and losses on investments resulting from market fluctuations are reported in the accompanying consolidated statements of activities in the period that such fluctuations occur. Dividends are recorded on the ex-dividend date. Interest income is recognized as earned. 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.

[8] 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.

[9] 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.

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, 2022 and 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 either of the years ended June 30, 2022 or 2021.

[10] Prepaid expenses:

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

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[11] Research grants payable:

Conditional grants and promises to give are not recorded as expenses until the condition on which they depend have been met. A grant is deemed to be conditional if it includes one or more measurable 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, 2022 and 2021, there were no grant awards awaiting approval.

[12] 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 and the Registry capitalize 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 years ended June 30, 2022 and 2021 was \$45,879 and \$52,627, respectively.

[13] Paycheck Protection Program:

The Organization has elected to account for the Paycheck Protection Program ("PPP") proceeds received under the Coronavirus Aid, Relief, and Economic Security Act ("CARES" Act) 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 forgiveness of PPP loan on the consolidated statements of activities.

[14] 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. An allowance for uncollectible pledges is provided based upon management's judgment, including such factors as prior collection history, type of contribution, and nature of fundraising activity, and is also based upon management's analysis of specific promises made. Management determined that no allowance was necessary as of both June 30, 2022 and 2021. 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.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[14] Revenue recognition: (continued)

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, 2022 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

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

Special events revenue is bifurcated into an exchange transaction component and a contribution component. The exchange transaction component is considered to be the fair market value benefits received by an attendee. The transaction price is estimated by management for each event based on an analysis of the benefits received by the attendee. The contribution component is considered to be the amount over and above the fair market value for which the attendee does not receive commensurate value. Revenue is recognized at the point in time when the event takes place as that is when the Organization's sole obligation to perform is satisfied and when the barriers are overcome. Payments for special events are generally required to be made when registration for the event occurs or sponsorships are made. The amounts are collected at the time of ticket purchase and are included in deferred revenue until recognized. As of June 30, 2022 and 2021, there were conditional contributions associated with special events of \$30,538 and \$75,934, respectively, which is included in deferred revenue on the consolidated statements of financial position. There were conditional contributions of \$640,000 as of July 1, 2020.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[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 legal and contributed IT services are recognized at fair value based on the current rates for similar legal and IT services and are included professional fees and management information systems, respectively, on the consolidated statements of functional expenses. The Organization also received contributed use of a space. The donated space and utilities are recorded at the fair value of the space and utilities provided and is included in the consolidated statements of functional expenses with rent. Contributed services for the years ended June 30, 2022 and 2021 are as follows:

Year Ended June 30, 2022				
	Program Services	Management and General	Fundraising	Total
IT services	\$ 1,000		\$ -	\$ 1,000
Legal	90,434	22,059	-	112,493
	<u>\$ 91,434</u>	<u>\$ 22,059</u>	<u>\$ -</u>	<u>\$ 113,493</u>
Year Ended June 30, 2021				
	Program Services	Management and General	Fundraising	Total
Legal	<u>\$ 40,128</u>	<u>\$ 8,567</u>	<u>\$ 8,567</u>	<u>\$ 57,262</u>

[16] New accounting pronouncement:

In September 2020, FASB issued Accounting Standards Update ("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 statements 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 June 15, 2021. The Organization adopted the standard on July 1, 2021 and was applied retroactively to July 1, 2020. The standard did not have a material impact on the consolidated financial statements.

[17] Upcoming accounting pronouncement:

In February 2016, FASB issued 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 2027 and management is currently evaluating the effect that this new guidance will have on its consolidated financial statements and related disclosures.

[18] Reclassification:

Certain amounts in the 2021 consolidated financial statements have been reclassified to conform to the current year presentation.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

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 statements of financial position date, comprise the following as of June 30, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Current financial assets:		
Cash and cash equivalents	\$ 1,161,722	\$ 1,233,928
Accounts receivable	726	-
Pledges receivable	2,677,367	2,317,407
Governmental grants receivable	61,248	41,891
Investments	<u>36,665,426</u>	<u>35,715,893</u>
Total current financial assets at year-end	<u>40,566,489</u>	<u>39,309,119</u>
Less amounts not available to be used within one year:		
Net assets with donor restrictions subject to expenditures for specified purposes	(519,943)	(1,800,000)
Board-designated for specific purpose	<u>(2,842,000)</u>	<u>(6,329,870)</u>
	<u>(3,361,943)</u>	<u>(8,129,870)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 37,204,546</u>	<u>\$ 31,179,249</u>

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.

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, 2022 and 2021 are as follows:

	<u>2022</u>	<u>2021</u>
Checking accounts	\$ 741,875	\$ 664,124
Savings accounts	<u>419,847</u>	<u>569,804</u>
	<u>\$ 1,161,722</u>	<u>\$ 1,233,928</u>

Savings accounts earn interest at a rate of 0.01% per annum as of June 30, 2022 and 2021. The Organization attempts to limit its credit risk associated with cash equivalents by utilizing highly-rated financial institutions.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE E - INVESTMENTS

Investments consist of the following as of June 30, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Investments:		
Common stock	\$ 12,663,347	\$ 5,032,022
Fixed income ETFs	3,311,868	11,526,882
Corporate bonds	1,171,237	1,193,454
Municipal bonds	118,315	140,003
Treasury bonds	691,816	3,055,059
Mutual funds	<u>10,450,826</u>	<u>5,000,000</u>
Investments measured at fair value	28,407,409	25,947,420
Certificate of deposit	-	2,000,000
Money market funds	<u>8,258,017</u>	<u>7,768,473</u>
Total investments	<u>\$ 36,665,426</u>	<u>\$ 35,715,893</u>

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 quoted prices for identical assets or liabilities in active markets.
- 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 ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE F - FAIR VALUE MEASUREMENTS (CONTINUED)

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 tables set forth, by level, the Organization's investment assets at fair value, within the aforementioned fair value hierarchy, as of June 30, 2022 and 2021:

Investment Assets at Fair Value as of June 30, 2022

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Common stock	\$ 12,663,347	\$ -	\$ -	\$ 12,663,347
Fixed income ETFs	3,311,868	-	-	3,311,868
Corporate bonds	-	1,171,237	-	1,171,237
Municipal bonds	-	118,315	-	118,315
Treasury bonds	-	691,816	-	691,816
Mutual funds	10,450,826	-	-	10,450,826
Total investment assets at fair value	<u>\$ 26,426,041</u>	<u>\$ 1,981,368</u>	<u>\$ -</u>	<u>\$ 28,407,409</u>

Investment Assets at Fair Value as of June 30, 2021

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
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
	<u>\$ 21,558,904</u>	<u>\$ 4,388,516</u>	<u>\$ -</u>	<u>\$ 25,947,420</u>

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 years ended June 30, 2022 and 2021, there were no transfers into or out of Levels 1, 2 or 3.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE G - GOVERNMENTAL GRANTS AND PLEDGES RECEIVABLE

Government grants and pledges receivable outstanding as of June 30, 2022 and 2021 are summarized as follows:

	2022	
	Pledges Receivable	Governmental Grants Receivable
Due within one year	\$ 2,677,367	\$ 61,248
Due within one to five years	5,433,333	-
Total receivables	8,110,700	61,248
Less total discounts to net present value	(245,243)	-
Total net receivables	\$ 7,865,457	\$ 61,248

	2021	
	Pledges Receivable	Governmental Grants Receivable
Due within one year	\$ 2,137,407	\$ 41,891
Due within one to five years	6,800,000	-
Total receivables	8,937,407	41,891
Less total discounts to net present value	(354,920)	-
Total net receivables	\$ 8,582,487	\$ 41,891

Pledges receivable are unconditional promises to give and are presented at net present value using discount factors ranging from 1.42% to 2.75% in both 2022 and 2021, as determined by management.

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 each of the years ended June 30, 2022 and 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 the commitment of \$5 million and \$6 million was not recorded in the consolidated statements of financial position as of June 30, 2022 and 2021, respectively, because the conditions for the commitment have not been met.

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

**Notes to Consolidated Financial Statements
June 30, 2022 and 2021**

NOTE I - RESEARCH GRANTS PAYABLE

Research grants payable as of June 30, 2022 and 2021 are summarized as follows:

	<u>2022</u>	<u>2021</u>
Research grants payable expected to be paid:		
Less than one year	\$ 1,307,983	\$ 780,217
One to five years	<u>487,676</u>	<u>715,979</u>
 Total research grants payable	 <u><u>\$ 1,795,659</u></u>	 <u><u>\$ 1,496,196</u></u>

NOTE J - NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are restricted for the following purposes or period as of June 30, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Subject to passage of time:		
Promises to give that are not restricted by donors	<u><u>\$ 6,031,907</u></u>	<u><u>\$ 5,779,972</u></u>
 Subject to expenditures for specified purpose:		
Research, Holloway Family Fund	1,418,776	1,466,567
Research, other	75,000	85,000
FTDDR Platform upgrade	85,000	-
Awareness	5,011	5,011
Comstock Grant Awards	13,200	
Promises to give, the proceeds from which have been restricted by donors for:		
Research, FTD Biomarkers	245,279	418,438
Research, FTD/ALS	<u>261,464</u>	<u>1,000,932</u>
	<u><u>2,103,730</u></u>	<u><u>2,975,948</u></u>
	<u><u>\$ 8,135,637</u></u>	<u><u>\$ 8,755,920</u></u>

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

**Notes to Consolidated Financial Statements
June 30, 2022 and 2021**

NOTE J - NET ASSETS WITH DONOR RESTRICTIONS (CONTINUED)

Net assets were released from donor restriction by incurring expenses satisfying the restricted purpose specified by the donors as follows for the years ended June 30, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Satisfaction of time restriction:		
Funds received	\$ 1,075,000	\$ 1,181,889
Satisfaction of purpose restriction:		
Research, Holloway Family Fund	1,047,791	-
Research, FTD Biomarkers	189,219	963,697
Research, Target ALS	756,151	1,305,181
Research, other	85,000	660,576
Awareness	-	7,369
Volunteer Program Expansion	-	104,162
	<u>\$ 3,153,161</u>	<u>\$ 4,222,874</u>

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 an additional amount for monthly operating expenses which increases annually. The monthly amount increased from \$5,049 to \$5,783 effective December 2021. 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 is being 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 statements of financial position.

Schedule future annual lease payments under all operating leases as of June 30, 2022 are as follows:

<u>Year Ending June 30,</u>	<u>Amount</u>
2023	\$ 166,346
2024	170,496
2025	147,646
2026	178,796
2027	167,556
	<u><u>\$ 830,840</u></u>

Total rental expense on the above lease for the years ended June 30, 2022 and 2021 was \$228,201 and \$220,507, respectively.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Consolidated Financial Statements June 30, 2022 and 2021

NOTE L - CONTINGENT GRANT AWARDS

The Organization offers Comstock Respite Grants to caregivers to help full-time, unpaid care partners attend to their own emotional, psychological and physical well-being. AFTD also offers Comstock 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 and are included in grants awarded on the statements of functional expenses. As of June 30, 2022 and 2021, there were \$28,137 and \$24,964, respectively, 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 \$14,000 for calendar year 2022, or \$17,000 if over age 50. The Organization must match 3% in at least three out of every five consecutive years. For the years ended June 30, 2022 and 2021, the employer match was \$83,375 and \$57,316, respectively.

NOTE N - RELATED PARTY TRANSACTIONS

A Board member of AFTD is a substantial contributor for the years ended June 30, 2022 and 2021. Contributions, including promises to give, from this contributor for the years ended June 30, 2022 and 2021 were \$3,020,150 and \$20,013,451, respectively. In addition, the Board member is an officer of a foundation that is a substantial contributor to AFTD. Contributions from the foundation were \$850,000 for each of the years ended June 30, 2022 and 2021. Contributions receivable from the foundation were \$6,580,919 and \$8,645,080 as of June 30, 2022 and 2021, respectively.

An additional Board member of AFTD is also a substantial contributor to the Organization. Donations for the years ended June 30, 2022 and 2021 were \$1,000,000 and \$2,032,143, respectively.

The Bluefield Project to Cure Frontotemporal Dementia is a co-founder of the Registry and has a 50% Member interest in the Registry. 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 \$200,000 and \$150,000 in contributed income for the years ended June 30, 2022 and 2021, respectively.

Dianna Wheaton, the Registry Director, has a personal relationship with a key contractor used by the Registry during the year ended June 30, 2021. The contract was managed by the President of the Registry. Payments to the contractor totaled \$-0- and \$75,621 for the years ended June 30, 2022 and 2021, respectively.

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 ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND
FTD DISORDERS REGISTRY LLC**

**Notes to Consolidated Financial Statements
June 30, 2022 and 2021**

NOTE O - COMMITMENTS AND CONTINGENCIES (CONTINUED)

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 December 14, 2022, which is the date the consolidated financial statements were available to be issued.

SUPPLEMENTARY INFORMATION

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

**Consolidating Schedule of Financial Position
June 30, 2022**

	The Association for Frontotemporal Degeneration	FTD Disorders Registry LLC	Eliminations	Consolidated Total
ASSETS				
Current assets:				
Cash and cash equivalents	\$ 101,450	\$ 1,060,272	\$ -	\$ 1,161,722
Accounts receivable	1,983	-	1,257	726
Pledges receivable	2,677,367	-	-	2,677,367
Governmental grants receivable	-	61,248	-	61,248
Investments	36,665,426	-	-	36,665,426
Prepaid expenses	90,160	1,271	-	91,431
Total current assets	39,536,386	1,122,791	1,257	40,657,920
Pledges receivable, net of current portion and discount	5,188,090	-	-	5,188,090
Software and equipment, net of accumulated depreciation of \$232,768	46,430	-	-	46,430
Security deposit	26,063	-	-	26,063
	<u>\$ 44,796,969</u>	<u>\$ 1,122,791</u>	<u>\$ 1,257</u>	<u>\$ 45,918,503</u>
LIABILITIES				
Current liabilities:				
Accounts payable and accrued expenses	\$ 324,157	\$ 37,184	\$ 1,257	\$ 360,084
Deferred revenues	30,538	-	-	30,538
Research grants payable	1,307,983	-	-	1,307,983
Total current liabilities	1,662,678	37,184	1,257	1,698,605
Research grants payable	487,676	-	-	487,676
Deferred rent	77,040	-	-	77,040
Total liabilities	<u>2,227,394</u>	<u>37,184</u>	<u>1,257</u>	<u>2,263,321</u>
NET ASSETS				
Net assets without donor restrictions:				
Undesignated	31,676,938	1,000,607	-	32,677,545
Board-designated	2,842,000	-	-	2,842,000
	34,518,938	1,000,607	-	35,519,545
Net assets with donor restrictions	8,050,637	85,000	-	8,135,637
Total net assets	<u>42,569,575</u>	<u>1,085,607</u>	<u>-</u>	<u>43,655,182</u>
	<u>\$ 44,796,969</u>	<u>\$ 1,122,791</u>	<u>\$ 1,257</u>	<u>\$ 45,918,503</u>

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

**Consolidating Schedule of Financial Position
June 30, 2021**

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

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

**Consolidating Schedule of Activities
Year Ended June 30, 2022**

	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	\$ 7,436,704	\$ 2,447,878	\$ 9,884,582	\$ 422,075	\$ 85,000	\$ 507,075	\$ 150,000	\$ 7,708,779	\$ 2,532,878	\$ 10,241,657
Government grants	-	-	-	220,600	-	220,600	-	220,600	-	220,600
Other income	16,706	-	16,706	42	-	42	12,211	4,537	-	4,537
In-kind contributions	86,909	-	86,909	91,040	-	91,040	64,456	113,493	-	113,493
Special event revenue	2,320,763	-	2,320,763	-	-	-	-	2,320,763	-	2,320,763
Less cost of direct benefit to donors	(170,259)	-	(170,259)	-	-	-	-	(170,259)	-	(170,259)
Net assets released from restrictions	3,153,161	(3,153,161)	-	-	-	-	-	3,153,161	(3,153,161)	-
	<u>12,843,984</u>	<u>(705,283)</u>	<u>12,138,701</u>	<u>733,757</u>	<u>85,000</u>	<u>818,757</u>	<u>226,667</u>	<u>13,351,074</u>	<u>(620,283)</u>	<u>12,730,791</u>
Expenses:										
Program services:										
Awareness and advocacy	1,589,047	-	1,589,047	-	-	-	-	1,589,047	-	1,589,047
Education and support	1,758,969	-	1,758,969	-	-	-	-	1,758,969	-	1,758,969
Research	3,825,017	-	3,825,017	-	-	-	150,000	3,675,017	-	3,675,017
FTD Registry	-	-	-	739,769	-	739,769	-	739,769	-	739,769
Total program services	<u>7,173,033</u>	<u>-</u>	<u>7,173,033</u>	<u>739,769</u>	<u>-</u>	<u>739,769</u>	<u>150,000</u>	<u>7,762,802</u>	<u>-</u>	<u>7,762,802</u>
Supporting services:										
Management and general	607,125	-	607,125	85,587	-	85,587	76,667	616,045	-	616,045
Fundraising	1,055,827	-	1,055,827	-	-	-	-	1,055,827	-	1,055,827
Total supporting services	<u>1,662,952</u>	<u>-</u>	<u>1,662,952</u>	<u>85,587</u>	<u>-</u>	<u>85,587</u>	<u>76,667</u>	<u>1,671,872</u>	<u>-</u>	<u>1,671,872</u>
	<u>8,835,985</u>	<u>-</u>	<u>8,835,985</u>	<u>825,356</u>	<u>-</u>	<u>825,356</u>	<u>226,667</u>	<u>9,434,674</u>	<u>-</u>	<u>9,434,674</u>
Change in net assets before other income	<u>4,007,999</u>	<u>(705,283)</u>	<u>3,302,716</u>	<u>(91,599)</u>	<u>85,000</u>	<u>(6,599)</u>	<u>-</u>	<u>3,916,400</u>	<u>(620,283)</u>	<u>3,296,117</u>
Other income:										
Investment loss, net	(3,618,583)	-	(3,618,583)	-	-	-	-	(3,618,583)	-	(3,618,583)
Change in net assets	<u>\$ 389,416</u>	<u>\$ (705,283)</u>	<u>\$ (315,867)</u>	<u>\$ (91,599)</u>	<u>\$ 85,000</u>	<u>\$ (6,599)</u>	<u>\$ -</u>	<u>\$ 297,817</u>	<u>\$ (620,283)</u>	<u>\$ (322,466)</u>

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

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	\$ 24,014,555	\$ 2,296,085	\$ 26,310,640	\$ 455,733	\$ -	\$ 455,733	\$ 150,000	\$ 24,320,288	\$ 2,296,085	\$ 26,616,373
Government grants	-	-	-	83,851	-	83,851	-	83,851	-	83,851
Other income	13,282	-	13,282	65,991	-	65,991	11,542	67,731	-	67,731
In-kind contributions	57,262	-	57,262	26,449	-	26,449	26,449	57,262	-	57,262
Special event revenue	1,531,438	-	1,531,438	-	-	-	-	1,531,438	-	1,531,438
Net assets released from restrictions	4,222,874	(4,222,874)	-	-	-	-	-	4,222,874	(4,222,874)	-
	29,839,411	(1,926,789)	27,912,622	632,024	-	632,024	187,991	30,283,444	(1,926,789)	28,356,655
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
FTD Registry	-	-	-	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	37,991	504,271	-	504,271
Fundraising	831,236	-	831,236	-	-	-	-	831,236	-	831,236
Total supporting services	1,233,812	-	1,233,812	139,686	-	139,686	37,991	1,335,507	-	1,335,507
	7,672,359	-	7,672,359	750,783	-	750,783	187,991	8,235,151	-	8,235,151
Change in net assets before other income	22,167,052	(1,926,789)	20,240,263	(118,759)	-	(118,759)	-	22,048,293	(1,926,789)	20,121,504
Other income:										
Investment income, net	1,417,832	-	1,417,832	-	-	-	-	1,417,832	-	1,417,832
Gain on forgiveness of PPP loan	300,500	-	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)	\$ -	\$ 23,821,225	\$ (1,926,789)	\$ 21,894,436

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

**Schedule of Functional Expenses – The Association for Frontotemporal Degeneration
Year Ended June 30, 2022**

	The Association for Frontotemporal Degeneration						
	Program Services				Supporting Services		
	Awareness and Advocacy	Education and Support	Research	Subtotal	Management and General	Fundraising	Total
Expenses:							
Salaries and wages	\$ 609,376	\$ 851,165	\$ 736,285	\$ 2,196,826	\$ 183,639	\$ 513,952	\$ 2,894,417
Payroll taxes	45,669	63,379	54,936	163,984	13,521	38,722	216,227
Employee benefits	81,003	109,979	95,198	286,180	19,254	65,038	370,472
Advertising	127,360	-	-	127,360	-	-	127,360
Bank and credit card processing fees	37	393	155	585	811	40,269	41,665
Conferences and meetings	154,871	142,276	397,987	695,134	39,636	3	734,773
Depreciation	2,429	3,036	1,822	7,287	2,428	2,429	12,144
Dues and subscriptions	2,155	4,429	8,416	15,000	2,836	1,824	19,660
Education - training	5,070	8,863	3,855	17,788	5,815	14,161	37,764
Events	145,376	-	152	145,528	-	165,985	311,513
Grants awarded	-	201,892	2,234,254	2,436,146	-	-	2,436,146
Insurance	4,459	7,803	3,344	15,606	3,018	3,344	21,968
Management Information Systems	169,889	176,667	91,202	437,758	63,967	110,155	611,880
Office and supplies	10,274	4,790	1,777	16,841	63,986	1,717	82,544
Postage and shipping	16,659	5,326	1,107	23,092	2,411	7,650	33,153
Printing and copying	63,072	3,727	40	66,839	401	10,122	77,362
Professional fees	99,133	71,742	148,680	319,555	162,379	41,623	523,557
Rent	45,640	79,870	34,230	159,740	36,717	34,230	230,687
Telecommunications and data	5,596	22,923	2,466	30,985	5,699	2,637	39,321
Travel	979	709	9,111	10,799	607	1,966	13,372
Total expenses included in the expense section on the statements of activities and changes in net assets	1,589,047	1,758,969	3,825,017	7,173,033	607,125	1,055,827	8,835,985
Plus expenses included with revenue on the statements of activities and changes in net assets:							
Cost of direct benefits to donors:							
Food and beverage	-	-	-	-	-	170,259	170,259
Total expenses	\$ 1,589,047	\$ 1,758,969	\$ 3,825,017	\$ 7,173,033	\$ 607,125	\$ 1,226,086	\$ 9,006,244

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

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

	The Association for Frontotemporal Degeneration							
	Program Services				Supporting Services			Total
	Awareness and Advocacy	Education and Support	Research	Subtotal	Management and General	Fundraising	Subtotal	
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

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

**Schedule of Functional Expenses – FTD Disorders Registry LLC
Year Ended June 30, 2022**

	<u>Program Services</u>	<u>General and Administrative</u>	<u>Total Expenses</u>
Salaries and wages	\$ 387,671	\$ 21,969	\$ 409,640
Payroll taxes	27,036	1,422	28,458
Employee benefits	58,039	4,952	62,991
Advertising	2,480	10,293	12,773
Bank and credit card processing fees	583	-	583
Depreciation	33,734	-	33,734
Dues and subscriptions	325	285	610
Insurance	-	4,588	4,588
Management Information Systems	198,386	-	198,386
Office and supplies	-	13,520	13,520
Postage and shipping	-	725	725
Printing and copying	-	45	45
Professional fees	25,584	19,110	44,694
Rent	-	2,777	2,777
Telecommunications and data	-	4,386	4,386
Travel	5,931	1,515	7,446
	<u>5,931</u>	<u>1,515</u>	<u>7,446</u>
Total expenses	<u>\$ 739,769</u>	<u>\$ 85,587</u>	<u>\$ 825,356</u>

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

**Schedule of Functional Expenses – FTD Disorders Registry LLC
Year Ended June 30, 2021**

	<u>Program Services</u>	<u>General and Administrative</u>	<u>Total Expenses</u>
Salaries and wages	\$ 265,051	\$ 72,567	\$ 337,618
Payroll taxes	20,126	2,327	22,453
Employee benefits	44,339	4,657	48,996
Advertising	471	-	471
Bank and credit card processing fees	-	600	600
Depreciation	40,481	-	40,481
Dues and subscriptions	-	560	560
Insurance	-	4,502	4,502
Management Information Systems	239,398	284	239,682
Office and supplies	1,231	3,035	4,266
Postage and shipping	-	239	239
Professional fees	-	47,115	47,115
Rent	-	1,339	1,339
Telecommunications and data	-	2,461	2,461
	<u> </u>	<u> </u>	<u> </u>
Total expenses	<u>\$ 611,097</u>	<u>\$ 139,686</u>	<u>\$ 750,783</u>