

THE ASSOCIATION FOR
FRONTOTEMPORAL DEGENERATION
AND
FTD DISORDERS REGISTRY LLC

CONSOLIDATED FINANCIAL STATEMENTS

JUNE 30, 2024 and 2023
(with 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 financial statements of The Association for Frontotemporal Degeneration and FTD Disorders Registry LLC (together, the "Organization"), which comprise the consolidated statements of financial position as of June 30, 2024 and 2023, 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 financial statements.

In our opinion, the accompanying financial statements 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, 2024 and 2023, 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, and for 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.

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 audits, significant audit findings, and certain internal control-related matters that we identified during the audits.

Supplementary Information

Our audits were conducted for the purpose of forming an opinion on the financial statements as a whole. The accompanying supplementary information shown on pages 24 to 31 is presented for purposes of additional analysis and is not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been 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 24 to 31 is fairly stated in all material respects in relation to the financial statements as a whole.

EisnerAmper LLP

EISNERAMPER LLP
Philadelphia, Pennsylvania
October 30, 2024



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

Consolidated Statements of Financial Position

	June 30,	
	2024	2023
ASSETS		
Current assets:		
Cash and cash equivalents	\$ 872,545	\$ 558,161
Accounts receivable	56,498	-
Pledges receivable	1,565,638	2,323,334
Governmental grants receivable	60,805	76,330
Investments	47,153,071	42,383,674
Prepaid expenses	101,371	149,885
Total current assets	49,809,928	45,491,384
Pledges receivable, net of current portion and discount	5,663,561	3,222,219
Software and equipment, net of accumulated depreciation of \$63,665 in 2024 and \$245,537 in 2023	361,981	159,161
Operating lease right-of-use asset	449,977	598,326
Security deposit	26,063	26,063
	<u>\$ 56,311,510</u>	<u>\$ 49,497,153</u>
LIABILITIES		
Current liabilities:		
Accounts payable and accrued expenses	\$ 1,062,789	\$ 596,060
Deferred revenues	421,417	198,744
Research grants payable	1,439,688	629,791
Current portion of operating lease liability	167,133	170,496
Total current liabilities	3,091,027	1,595,091
Research grants payable	295,000	422,387
Long-term operating lease liability	340,656	497,331
Total liabilities	<u>3,726,683</u>	<u>2,514,809</u>
Commitments		
NET ASSETS		
Net assets without donor restrictions:		
Undesignated	40,283,205	35,696,345
Board-designated	1,678,649	2,178,649
	41,961,854	37,874,994
Net assets with donor restrictions	<u>9,621,130</u>	<u>8,143,659</u>
Total net assets controlling interest	51,582,984	46,018,653
Noncontrolling interest	<u>1,001,843</u>	<u>963,691</u>
Total net assets	<u>52,584,827</u>	<u>46,982,344</u>
	<u>\$ 56,311,510</u>	<u>\$ 49,497,153</u>

See notes to financial statements.

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

Consolidated Statements of Activities

	Year Ended June 30,					
	2024			2023		
	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	\$ 4,875,381	\$ 5,998,086	\$ 10,873,467	\$ 5,240,213	\$ 2,532,930	\$ 7,773,143
Government grants	73,300	-	73,300	223,260	-	223,260
Other income	198,777	-	198,777	25,583	-	25,583
Contributed services	158,812	-	158,812	140,481	-	140,481
Special event revenue, net of cost of direct benefits to donors of \$174,240 in 2024 and \$178,807 in 2023	1,885,502	-	1,885,502	1,803,277	-	1,803,277
Net assets released from restrictions	4,520,615	(4,520,615)	-	2,524,908	(2,524,908)	-
	11,712,387	1,477,471	13,189,858	9,957,722	8,022	9,965,744
Expenses:						
Program services:						
Awareness and advocacy	2,871,133	-	2,871,133	2,292,337	-	2,292,337
Education and support	2,170,006	-	2,170,006	2,131,764	-	2,131,764
Research	4,637,316	-	4,637,316	2,904,814	-	2,904,814
FTD Registry	798,934	-	798,934	806,578	-	806,578
Total program services	10,477,389	-	10,477,389	8,135,493	-	8,135,493
Supporting services:						
Management and general	613,847	-	613,847	716,101	-	716,101
Fundraising	1,335,076	-	1,335,076	1,363,135	-	1,363,135
Total supporting services	1,948,923	-	1,948,923	2,079,236	-	2,079,236
	12,426,312	-	12,426,312	10,214,729	-	10,214,729
Change in net assets before other income	(713,925)	1,477,471	763,546	(257,007)	8,022	(248,985)
Other income:						
Investment income , net	4,838,937	-	4,838,937	3,576,147	-	3,576,147
Change in net assets	4,125,012	1,477,471	5,602,483	3,319,140	8,022	3,327,162
Change in net assets attributable to the noncontrolling interest	38,152	-	38,152	463,387	(42,500)	420,887
Change in net assets attributable to the controlling interest	\$ 4,086,860	\$ 1,477,471	\$ 5,564,331	\$ 2,855,753	\$ 50,522	\$ 2,906,275

See notes to financial statements.

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

**Consolidated Statements of Changes in Net Assets
Years Ended June 30, 2024 and 2023**

	<u>Controlling Interest</u>		<u>Noncontrolling Interest</u>		<u>Total</u>
	<u>Net Assets Without Donor Restrictions</u>	<u>Net Assets With Donor Restrictions</u>	<u>Net Assets Without Donor Restrictions</u>	<u>Net Assets With Donor Restrictions</u>	
Net assets at July 1, 2022	\$ 35,019,241	\$ 8,093,137	\$ 500,304	\$ 42,500	\$ 43,655,182
Change in net assets	<u>2,855,753</u>	<u>50,522</u>	<u>463,387</u>	<u>(42,500)</u>	<u>3,327,162</u>
Net assets at June 30, 2023	37,874,994	8,143,659	963,691	-	46,982,344
Change in net assets	<u>4,086,860</u>	<u>1,477,471</u>	<u>38,152</u>	<u>-</u>	<u>5,602,483</u>
Net assets at June 30, 2024	<u>\$ 41,961,854</u>	<u>\$ 9,621,130</u>	<u>\$ 1,001,843</u>	<u>\$ -</u>	<u>\$ 52,584,827</u>

See notes to financial statements.

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

**Consolidated Statement of Functional Expenses
Year Ended June 30, 2024**

	Program Services				Supporting Services			Total	
	Awareness and Advocacy	Education and Support	Research	FTD Registry	Subtotal	Management and General	Fundraising		Subtotal
Expenses:									
Salaries and wages	\$ 1,540,705	\$ 992,454	\$ 1,006,372	\$ 428,930	\$ 3,968,461	\$ 313,051	\$ 695,327	\$ 1,008,378	\$ 4,976,839
Payroll taxes and related benefits	302,370	195,803	195,004	91,825	785,002	60,732	139,621	200,353	985,355
Advertising	162,297	-	-	6,094	168,391	-	-	-	168,391
Bank and credit card processing fees	173	34	454	27	688	1,840	57,441	59,281	59,969
Conferences and meetings - facilities and other costs	18,075	290,392	426,430	-	734,897	13,473	670	14,143	749,040
Depreciation	2,800	592	3,119	11,429	17,940	774	1,821	2,595	20,535
Dues and subscriptions	7,104	1,767	208,505	-	217,376	4,877	3,505	8,382	225,758
Education - training	8,702	6,995	1,221	422	17,340	10,778	6,888	17,666	35,006
Equipment	8,652	5,989	5,643	-	20,284	3,781	-	3,781	24,065
Events - facilities and other costs	134,572	-	-	-	134,572	-	32,465	32,465	167,037
Grants awarded	-	241,506	2,434,999	-	2,676,505	-	-	-	2,676,505
Insurance	10,865	7,761	4,890	-	23,516	8,122	6,078	14,200	37,716
Management information systems	193,698	119,788	81,564	176,550	571,600	28,712	73,183	101,895	673,495
Office and supplies	10,496	7,956	3,546	252	22,250	11,270	7,420	18,690	40,940
Postage and shipping	17,899	8,421	1,283	-	27,603	1,765	15,771	17,536	45,139
Printing and copying	78,533	9,421	7,969	-	95,923	693	35,743	36,436	132,359
Professional fees	240,981	82,910	118,073	74,846	516,810	115,114	144,784	259,898	776,708
Recruitment	796	1,385	399	402	2,982	4,456	1,603	6,059	9,041
Rent	75,116	65,554	37,238	-	177,908	18,620	44,905	63,525	241,433
Telecommunications and data	11,402	27,067	6,024	1,391	45,884	2,200	5,541	7,741	53,625
Travel	45,897	104,211	94,583	6,766	251,457	13,589	62,310	75,899	327,356
Total expenses included in the expenses section on the consolidated statements of activities	2,871,133	2,170,006	4,637,316	798,934	10,477,389	613,847	1,335,076	1,948,923	12,426,312
Plus expenses included with revenue section on the consolidated statements of activities:									
Cost of direct benefits to donors:									
Food, beverage and greens fees	-	-	-	-	-	-	174,240	174,240	174,240
Total expenses	\$ 2,871,133	\$ 2,170,006	\$ 4,637,316	\$ 798,934	\$ 10,477,389	\$ 613,847	\$ 1,509,316	\$ 2,123,163	\$ 12,600,552

See notes to financial statements.

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

**Consolidated Statement of Functional Expenses
Year Ended June 30, 2023**

	Program Services				Supporting Services			Total	
	Awareness and Advocacy	Education and Support	Research	FTD Registry	Subtotal	Management and General	Fundraising		Subtotal
Expenses:									
Salaries and wages	\$ 1,174,272	\$ 919,782	\$ 867,548	\$ 368,676	\$ 3,330,278	\$ 268,578	\$ 762,323	\$ 1,030,901	\$ 4,361,179
Payroll taxes and related benefits	232,354	186,890	175,426	89,127	683,797	44,105	153,318	197,423	881,220
Advertising	177,819	-	-	2,876	180,695	-	-	-	180,695
Bank and credit card processing fees	-	75	173	30	278	2,334	50,261	52,595	52,873
Conferences and meetings - facilities and other costs	27,198	370,184	129,414	115	526,911	45,962	-	45,962	572,873
Depreciation	2,554	3,192	1,915	-	7,661	2,554	2,554	5,108	12,769
Dues and subscriptions	4,829	1,293	7,382	200	13,704	4,969	3,093	8,062	21,766
Education - training	10,569	11,752	7,870	-	30,191	61,003	15,920	76,923	107,114
Equipment	-	-	85	-	85	35,221	2,000	37,221	37,306
Events - facilities and other costs	124,356	-	-	-	124,356	4,501	164,068	168,569	292,925
Grants awarded	95,023	324,435	1,506,341	-	1,925,799	-	-	-	1,925,799
Insurance	5,770	10,097	4,327	-	20,194	11,336	4,327	15,663	35,857
Management information systems	205,128	161,103	98,008	204,008	668,247	90,059	98,410	188,469	856,716
Office and supplies	4,461	3,106	851	-	8,418	24,241	1,048	25,289	33,707
Postage and shipping	10,510	2,268	734	163	13,675	4,380	16,069	20,449	34,124
Printing and copying	57,036	1,699	4,033	-	62,768	1,015	26,375	27,390	90,158
Professional fees	67,327	21,071	20,148	130,362	238,908	61,772	17,798	79,570	318,478
Recruitment	13,566	1,106	394	-	15,066	5,648	852	6,500	21,566
Rent	45,267	79,217	33,950	-	158,434	35,630	33,950	69,580	228,014
Telecommunications and data	5,483	27,504	4,145	-	37,132	10,330	3,695	14,025	51,157
Travel	28,815	6,990	42,070	11,021	88,896	2,463	7,074	9,537	98,433
Total expenses included in the expenses section on the consolidated statements of activities	2,292,337	2,131,764	2,904,814	806,578	8,135,493	716,101	1,363,135	2,079,236	10,214,729
Plus expenses included with revenue section on the consolidated statements of activities:									
Cost of direct benefits to donors:									
Food, beverage and greens fees	-	-	-	-	-	-	178,807	178,807	178,807
Total expenses	<u>\$ 2,292,337</u>	<u>\$ 2,131,764</u>	<u>\$ 2,904,814</u>	<u>\$ 806,578</u>	<u>\$ 8,135,493</u>	<u>\$ 716,101</u>	<u>\$ 1,541,942</u>	<u>\$ 2,258,043</u>	<u>\$ 10,393,536</u>

See notes to financial statements.

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

Consolidated Statements of Cash Flows

	Year Ended June 30,	
	<u>2024</u>	<u>2023</u>
Cash flows from operating activities:		
Change in net assets	\$ 5,602,483	\$ 3,327,162
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation	20,535	12,769
Amortization of right-of-use asset	148,349	145,530
Amortization of discount on pledges receivable	(71,996)	(109,130)
Donated securities	(108,989)	(161,062)
Proceeds from sale of donated securities	108,416	159,327
Net realized and unrealized gain on investments	(3,600,166)	(2,471,249)
(Increase) decrease in assets:		
Accounts receivable	(56,498)	726
Pledges receivable	(411,324)	2,429,034
Governmental grants receivable	15,525	(15,082)
Prepaid expenses	48,514	(58,454)
Increase (decrease) in liabilities:		
Accounts payable and accrued expenses	466,729	235,976
Deferred revenues	222,673	168,206
Research grants payable	682,510	(743,481)
Operating lease liability	(160,038)	(153,069)
Net cash provided by operating activities	<u>2,906,723</u>	<u>2,767,203</u>
Cash flows from investing activities:		
Proceeds from sale of investments	14,614,259	7,362,086
Purchase of investments	(16,983,243)	(10,607,350)
Purchase of equipment	(223,355)	(125,500)
Net cash used in investing activities	<u>(2,592,339)</u>	<u>(3,370,764)</u>
Net increase (decrease) in cash and cash equivalents	314,384	(603,561)
Cash and cash equivalents at beginning of year	<u>558,161</u>	<u>1,161,722</u>
Cash and cash equivalents at end of year	<u><u>\$ 872,545</u></u>	<u><u>\$ 558,161</u></u>

See notes to financial statements.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Financial Statements June 30, 2024 and 2023

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 with FTD 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.

AFTD is 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 is governed by a Limited Liability Company Agreement ("LLC Agreement"), which was amended and restated as of September 10, 2020, which defines the roles and responsibilities of the members and management of the Registry. 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").

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 Financial Statements June 30, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

[1] Principles of consolidation:

Because AFTD is the managing member of the Registry with the responsibilities for oversight of all the Registry's day-to-day activities, the accompanying financial statements include the accounts of The Association for Frontotemporal Degeneration and the FTD Disorders Registry LLC (together, 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 the FTD Disorders Registry LLC as of both June 30, 2024 and 2023 since this interest is not directly controlled by AFTD.

[2] Basis of accounting:

The accompanying 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 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 financial statements may include the following classes of net assets:

(i) *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. In January 2022, the AFTD Board voted to create two 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, 2024 and 2023 was \$1,550,000 and \$1,800,000, respectively. 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, 2024 and 2023 was \$128,649 and \$378,649, respectively.

(ii) *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 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 dates of the financial statements and the reported amounts of revenues and expenses during the reporting periods. Actual results could differ from those estimates.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Financial Statements June 30, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[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.

[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 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 financial statements.

[8] Accounts receivable and allowance for credit losses:

Accounts receivable consists primarily of special event revenue receivable and are stated at amounts management expects to collect from outstanding balances. The estimate for the allowance for expected credit losses is derived from a review of the Organizations' historical experience and management's evaluation of outstanding accounts receivable. The estimate is adjusted for management's assessment of current conditions, reasonable and supportable forecasts regarding future events, and any other factors deemed relevant by the Organization. Balances that are still outstanding after management has used reasonable collection efforts are written off. Management has determined that an allowance is deemed immaterial as of June 30, 2024 or 2023.

[9] 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, professional development, 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.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Financial Statements June 30, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[10] 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, 2024 and 2023, there are no uncertain tax positions taken or expected to be taken that would require recognition of a liability or disclosure in the 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, 2024 or 2023.

[11] Prepaid expenses:

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

[12] 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, 2024 and 2023, there were no grant awards awaiting approval.

[13] Software and equipment:

Equipment is stated at their original costs at the dates of acquisition, or, if contributed, at their fair values at the dates of donation, net of accumulated depreciation and amortization. The Organization records as assets those items of property and equipment that have a cost of \$5,000 or more and a useful life greater than one year, whereas minor costs of repairs and maintenance are expensed as incurred.

Depreciation of equipment is provided using the straight-line method over the estimated useful lives of the respective assets ranging from three to five years.

The costs of internally developed software of the strategic infrastructure projects have been capitalized in accordance with the provisions of the Financial Accounting Standards Board ("FASB") Accounting Standards Codification ("ASC") Topic 350, *Intangibles - Goodwill and Other - Internal-Use Software*, and costs incurred during the preliminary project work stage or conceptual stage, such as determining the performance requirements, system requirements, and data conversion, are expensed as incurred. Costs incurred in the application development phase, such as coding, testing for new software, and upgrades that result in additional functionality, are capitalized and are amortized using the straight-line method over the useful life of the software, ranging from four to seven years. Amortization of these capitalized costs begins only when the software becomes ready for its intended use. Costs incurred during the postimplementation/operation stage, including training costs and maintenance costs, are expensed as incurred. During the years ended June 30, 2024 and 2023, the Organization did not capitalize any internally developed software projects.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Financial Statements June 30, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[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, 2024 and 2023. 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, 2024 or 2023 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.

Membership fees

During the fiscal year ended June 30, 2023, the Organization established a membership-based Research Roundtable, convening leading FTD research stakeholders for collaboration. Revenue from membership fees is recognized upon the completion of the annual meeting of the stakeholders to be held subsequent to June 30, 2024 and 2023. The amount of dues is considered commensurate with the benefit received, therefore, the entire amount is considered an exchange transaction. Total fees collected during the fiscal year ended June 30, 2024 and 2023 were \$250,000 and \$140,000, respectively, and are included in deferred revenue as of June 30, 2024 and 2023.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Financial Statements June 30, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[14] Revenue recognition: (continued)

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, 2024 and 2023, there were conditional contributions associated with special events of \$36,317 and \$58,744, respectively, which is included in deferred revenue on the consolidated statements of financial position.

[15] Contributed Services:

For recognition of contributed services in the financial statements, such services must: (i) create or enhance non-financial assets, (ii) typically need to be acquired not provided by donation, (iii) require specialized skills, and (iv) be provided by individuals possessing these skills. Contributed services are recorded at their estimated fair value at the dates of contribution and are reported as without donor restrictions in the consolidated statements of activities. The fair values of contributed services provided by the Organization totaled \$158,812 and \$140,481 for fiscal-years 2024 and 2023, respectively, and these amounts have been recorded as revenue and expense in the consolidated statements of activities. Other contributed services provided to the Institute, such as those by volunteers, are not reported in the financial statements because they do not meet the criteria for recognition.

[16] Leases:

The Organization determines if an arrangement is a lease at inception. For the Organization's operating leases, a right-of-use ("ROU") asset represents the Organization's right to use an underlying asset for the lease term and an operating lease liability represents an obligation to make lease payments arising from the lease. The ROU asset and lease liability are recognized at the lease commencement date based on the present value of lease payments over the lease term. Since the Organization's lease agreements do not provide an implicit interest rate, the Organization uses a risk-free rate based on the information available at the commencement date in determining the present value of the lease payments. Operating lease expense is recognized on a straight-line basis over the lease term, subject to any changes in the lease or expectations regarding the terms. Variable lease costs, such as operating costs, are expensed as incurred.

[17] Recently adopted accounting pronouncement:

Effective July 1, 2023, the Organization adopted FASB Accounting Standards Update ("ASU") No. 2016-13, Financial Instruments – Credit Losses (Topic 326) – Measurement of Credit Losses on Financial Instruments ("ASU 2016-13"), as amended. ASU 2016-13 replaces the "incurred loss" credit losses Framework with an expected loss methodology that is referred to as the current expected credit loss ("CECL") methodology, which requires management's measurement of the allowance for credit losses to be based on a broader range of reasonable and supportable information for lifetime credit loss estimates. Results for the year ended June 30, 2023 continue to be reported in accordance with previously applicable U.S. GAAP. The adoption and application of the standard had no material effect on these financial statements.

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

**Notes to Financial Statements
June 30, 2024 and 2023**

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[18] Reclassification:

Certain amounts in the 2023 consolidated statement of functional expenses have been reclassified to conform to the current year presentation.

[19] Subsequent events:

The Organization evaluated subsequent events through October 30, 2024, the date on which the financial statements were available to be issued.

NOTE C - LIQUIDITY AND AVAILABILITY OF RESOURCES

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, 2024 and 2023:

	<u>2024</u>	<u>2023</u>
Current financial assets:		
Cash and cash equivalents	\$ 872,545	\$ 558,161
Accounts receivable	56,498	-
Pledges receivable	1,565,638	2,323,334
Governmental grants receivable	60,805	76,330
Investments	<u>47,153,071</u>	<u>42,383,674</u>
Total financial assets available within one year	<u>49,708,557</u>	<u>45,341,499</u>
Less:		
Amounts unavailable for general expenditure with one year, due to:		
Restrictions by donors with purpose restrictions	(91,500)	(118,102)
Board-designated for specific purpose	<u>(1,678,649)</u>	<u>(2,178,649)</u>
Total amounts unavailable for general expenditure within one year	<u>(1,770,149)</u>	<u>(2,296,751)</u>
Total financial assets available to meet cash needs for general expenditures within one year	<u>\$ 47,938,408</u>	<u>\$ 43,044,748</u>

The Organization has a policy to structure its financial assets to be available as its general expenditures, liabilities, and other obligations come due. Additionally, the Organization's Board-designated net assets, while designated for specific purposes, could be made available for current operations, if necessary; however, the Organization does not intend to spend these funds for purposes other than those approved by the Board of Directors.

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

**Notes to Financial Statements
June 30, 2024 and 2023**

NOTE D - INVESTMENTS

At each fiscal year end, investments consisted of the following:

	June 30,	
	2024	2023
Investments:		
Common stock	\$ 27,115,005	\$ 19,074,738
Fixed income ETFs	1,969,622	2,249,447
Fixed income funds	699,203	1,090,012
Corporate bonds	5,206,124	3,431,885
Municipal bonds	113,825	115,964
Treasury bonds	1,905,580	1,320,212
Mutual funds	5,334,425	7,116,573
	42,343,784	34,398,831
Investments measured at fair value	4,809,287	7,984,843
	\$ 47,153,071	\$ 42,383,674
Total investments		

NOTE E - 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 Financial Statements
June 30, 2024 and 2023**

NOTE E - FAIR VALUE MEASUREMENTS (CONTINUED)

The following tables summarize the fair values of the Organization's investments at each fiscal year end, in accordance with the FASB's ASC Topic 820 valuation levels:

Investment Assets at Fair Value as of June 30, 2024

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Common stock	\$ 27,115,005	\$ -	\$ -	\$ 27,115,005
Fixed income ETFs	1,969,622	-	-	1,969,622
Fixed income funds	699,203	-	-	699,203
Corporate bonds	-	5,206,124	-	5,206,124
Municipal bonds	-	113,825	-	113,825
Treasury bonds	-	1,905,580	-	1,905,580
Mutual funds	5,334,425	-	-	5,334,425
	<u>\$ 35,118,255</u>	<u>\$ 7,225,529</u>	<u>\$ -</u>	<u>\$ 42,343,784</u>
Total investment assets at fair value				

Investment Assets at Fair Value as of June 30, 2023

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Common stock	\$ 19,074,738	\$ -	\$ -	\$ 19,074,738
Fixed income ETFs	2,249,447	-	-	2,249,447
Fixed income funds	1,090,012	-	-	1,090,012
Corporate bonds	-	3,431,885	-	3,431,885
Municipal bonds	-	115,964	-	115,964
Treasury bonds	-	1,320,212	-	1,320,212
Mutual funds	7,116,573	-	-	7,116,573
	<u>\$ 29,530,770</u>	<u>\$ 4,868,061</u>	<u>\$ -</u>	<u>\$ 34,398,831</u>
Total investment assets at fair value				

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, 2024 and 2023, 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 Financial Statements
June 30, 2024 and 2023**

NOTE F - SOFTWARE AND EQUIPMENT

At each fiscal year end, software and equipment consisted of the following:

	June 30,	
	2024	2023
Software	\$ 348,855	\$ 327,907
Office equipment	76,791	76,791
	425,646	404,698
Less: accumulated depreciation	(63,665)	(245,537)
	\$ 361,981	\$ 159,161

During 2024, the Organization disposed of software no longer in use with an original cost basis of approximately \$202,000. There was no gain or loss on the disposition. There were no disposals in 2023.

For the years ended June 30, 2024 and 2023, depreciation expense was \$20,535 and \$12,769, respectively.

NOTE G - PLEDGES RECEIVABLE

Governmental grants and pledges receivable outstanding as of June 30, 2024 and 2023 are summarized as follows:

	2024	
	Pledges Receivable	Governmental Grants Receivable
Due within one year	\$ 1,565,638	\$ 60,805
Due within one to five years	7,000,000	-
Total receivables	8,565,638	60,805
Less: total discounts to net present value	(1,336,439)	-
Total net receivables	\$ 7,229,199	\$ 60,805

	2023	
	Pledges Receivable	Governmental Grants Receivable
Due within one year	\$ 2,323,334	\$ 76,330
Due within one to five years	3,358,332	-
Total receivables	5,681,666	76,330
Less: total discounts to net present value	(136,113)	-
Total net receivables	\$ 5,545,553	\$ 76,330

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

**Notes to Financial Statements
June 30, 2024 and 2023**

NOTE G - PLEDGES RECEIVABLE (CONTINUED)

Pledges receivable are unconditional promises to give and are presented at net present value using discount factors ranging from 1.42% to 4.19% in 2024 and discount factors ranging from 1.42% to 2.71% in 2023, 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, 2024 and 2023, the Organization recognized \$1 million of contribution revenue on this conditional commitment due to the receipt of the annual installment of the original \$10 million pledge. In accordance with professional standards, the balance of the commitment of \$3 million and \$4 million was not recorded in the consolidated statements of financial position as of June 30, 2024 and 2023, respectively, because the conditions for the commitment have not been met.

NOTE I - RESEARCH GRANTS PAYABLE

At each fiscal year end, grants and fellowships payable consisted of the following:

	<u>2024</u>	<u>2023</u>
Due to be paid within one year	\$ 1,439,688	\$ 629,791
Due to be paid between two and five years	<u>295,000</u>	<u>422,387</u>
Total research grants payable	<u>\$ 1,734,688</u>	<u>\$ 1,052,178</u>

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

**Notes to Financial Statements
June 30, 2024 and 2023**

NOTE J - NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are restricted for the following purposes or period as of June 30, 2024 and 2023:

	<u>2024</u>	<u>2023</u>
Subject to passage of time:		
Promises to give that are not restricted by donors	<u>\$ 3,583,801</u>	<u>\$ 5,103,470</u>
Subject to expenditures for specified purpose:		
Research, Holloway Family Fund	1,869,474	1,945,622
Research, other	65,833	574,940
Genetics initiatives	-	24,333
Strategic planning	46,500	-
Support and education	249,535	240,000
Awareness	5,010	5,011
Iqvia platform	73,300	-
Promises to give, the proceeds from which have been restricted by donors for:		
Research, Treat FTD	3,727,677	-
Research, FTD Biomarkers	-	132,181
Research, FTD/ALS	-	118,102
	<u>6,037,329</u>	<u>3,040,189</u>
	<u>\$ 9,621,130</u>	<u>\$ 8,143,659</u>

Net assets were released from donor restriction by incurring expenses satisfying the restricted purpose specified by the donors as follows for the fiscal years ended June 30, 2024 and 2023:

	<u>2024</u>	<u>2023</u>
Satisfaction of time restriction:		
Funds received	\$ 1,591,667	\$ 1,554,167
Satisfaction of purpose restriction:		
Research, Holloway Family Fund	1,076,149	473,153
Research, FTD Biomarkers	132,181	113,098
Research, Target ALS	118,102	151,763
Research, other	1,211,318	60
FTDDR Platform upgrade	-	85,000
Support and education	266,865	72,000
Genetic initiatives	124,333	-
Strategic planning	-	75,667
	<u>\$ 4,520,615</u>	<u>\$ 2,524,908</u>

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

**Notes to Financial Statements
June 30, 2024 and 2023**

NOTE K - LEASE AGREEMENT

AFTD leases its office facilities under a long-term, noncancelable operating lease which is recorded in accordance with ASC 842. The lease expires in May 2027. Monthly base rent under the lease is approximately \$14,000, with annual increases over the life of the lease. In addition, AFTD is responsible for its share of operating expenses, payable in monthly installments of approximately \$5,800, adjusted annually. AFTD paid the landlord a security deposit of \$26,063. In the agreement, the landlord provided AFTD with free rent for six months.

The liabilities under operating leases are recorded at the present value of the minimum lease payments. Lease expense of \$158,807 for both of the fiscal years ended June 30, 2024 and 2023, respectively, relating to operating leases, consisting of ROU asset amortization and lease liability interest, is included in rent on the consolidated statements of functional expenses.

The future minimum lease payments required under all operating leases at June 30, 2024 are as follows:

<u>Year Ending June 30,</u>	<u>2024</u>
2025	\$ 167,133
2026	178,796
2027	<u>175,069</u>
Total minimum lease payments	520,998
Less: amount representing interest	<u>(13,209)</u>
Amount reported on consolidated statements of financial position	<u>\$ 507,789</u>

<u>Year Ending June 30,</u>	<u>2024</u>	<u>2023</u>
Weighted average remaining lease term		
Operating leases	2.9 years	3.92 years
Weighted average discount rate		
Operating leases	1.80%	1.80%

<u>Reported as of June 30,</u>	<u>Operating Leases</u>	
	<u>2024</u>	<u>2023</u>
Current portion of lease liability	\$ 167,133	\$ 170,496
Lease liability, net of current portion	<u>340,656</u>	<u>497,331</u>
Total	<u>\$ 507,789</u>	<u>\$ 667,827</u>

The cash paid for amounts included in the measurement of lease liabilities was \$170,496 and \$166,346 for the fiscal years ended June 30, 2024 and 2023, respectively.

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

Notes to Financial Statements June 30, 2024 and 2023

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 consolidated statements of functional expenses. As of June 30, 2024 and 2023, there were \$119,500 and \$48,215, 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 \$16,000 for calendar year 2024, or \$19,500 if over age 50. The Organization must match 3% in at least three out of every five consecutive years. For the fiscal years ended June 30, 2024 and 2023, the employer match was \$130,498 and \$113,989, respectively.

NOTE N - RELATED PARTY TRANSACTIONS

A Board member of AFTD is a contributor for the fiscal years ended June 30, 2024 and 2023. Contributions, including promises to give, from this contributor for the fiscal years ended June 30, 2024 and 2023 were \$43,153 and \$11,010, respectively. In addition, the Board member is an officer of a foundation that is a substantial contributor to AFTD. Contributions from the foundation were \$4,577,678 and \$850,000 for the fiscal years ended June 30, 2024 and 2023, respectively. Contributions receivable from the foundation were \$6,663,562 and \$4,472,685 as of June 30, 2024 and 2023, respectively.

An additional Board member of AFTD is a substantial contributor to the Organization. Donations for the years ended June 30, 2024 and 2023 were \$1,002,000 and \$1,015,505, 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 serves as a voting member on the Registry's Board of Directors. The Registry received \$250,000 and \$600,000 in contributions for the years ended June 30, 2024 and 2023, respectively. Contributions receivable were \$0 and \$200,000 as of June 30, 2024 and 2023, respectively.

NOTE O - COMMITMENTS

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 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 financial statements.

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

**Notes to Financial Statements
June 30, 2024 and 2023**

NOTE P - CONTRIBUTED SERVICES

For the years ended June 30, 2024 and 2023, contributed nonfinancial assets recognized within the consolidated statements of activities include the following:

Year Ended June 30, 2024

	Revenue Recognized	Utilization in Programs/Activites	Donor Restrictions	Valuation Techniques and Inputs
Donated Legal Services	\$ 158,812	Utilized in operations for various program services matters of \$147,080 and administrative matters of \$11,732.	N/A	Contributed services are considered to reflect fair market value rates for services performed in the Philadelphia marketplace.

Year Ended June 30, 2023

	Revenue Recognized	Utilization in Programs/Activites	Donor Restrictions	Valuation Techniques and Inputs
Donated Legal Services	\$ 140,481	Utilized in operations for various program services matters of \$115,953 and administrative matters of \$24,528.	N/A	Contributed services are considered to reflect fair market value rates for services performed in the Philadelphia marketplace.

SUPPLEMENTARY INFORMATION

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

**Consolidating Schedule of Financial Position
June 30, 2024**

	The Association for Frontotemporal Degeneration	FTD Disorders Registry LLC	Eliminations	Consolidated Total
ASSETS				
Current assets:				
Cash and cash equivalents	\$ 572,093	\$ 300,452	\$ -	\$ 872,545
Accounts receivable	127,647	-	(71,149)	56,498
Pledges receivable	1,565,638	-	-	1,565,638
Governmental grants receivable	-	60,805	-	60,805
Investments	45,446,931	1,706,140	-	47,153,071
Prepaid expenses	95,209	6,162	-	101,371
	<u>47,807,518</u>	<u>2,073,559</u>	<u>(71,149)</u>	<u>49,809,928</u>
Total current assets				
Pledges receivable, net of current portion and discount	5,663,561	-	-	5,663,561
Software and equipment, net of accumulated depreciation of \$63,665	24,554	337,427	-	361,981
Operating lease right-of-use asset	449,977	-	-	449,977
Security deposit	26,063	-	-	26,063
	<u>\$ 53,971,673</u>	<u>\$ 2,410,986</u>	<u>\$ (71,149)</u>	<u>\$ 56,311,510</u>
LIABILITIES				
Current liabilities:				
Accounts payable and accrued expenses	\$ 726,636	\$ 407,302	\$ (71,149)	\$ 1,062,789
Deferred revenues	421,417	-	-	421,417
Research grants payable	1,439,688	-	-	1,439,688
Current portion of operating lease liability	167,133	-	-	167,133
	<u>2,754,874</u>	<u>407,302</u>	<u>(71,149)</u>	<u>3,091,027</u>
Total current liabilities				
Research grants payable	295,000	-	-	295,000
Long-term operating lease liability	340,656	-	-	340,656
	<u>3,390,530</u>	<u>407,302</u>	<u>(71,149)</u>	<u>3,726,683</u>
Total liabilities				
NET ASSETS				
Net assets without donor restrictions:				
Undesignated	39,354,664	1,930,384	-	41,285,048
Board-designated	1,678,649	-	-	1,678,649
	<u>41,033,313</u>	<u>1,930,384</u>	<u>-</u>	<u>42,963,697</u>
Net assets with donor restrictions	9,547,830	73,300	-	9,621,130
	<u>50,581,143</u>	<u>2,003,684</u>	<u>-</u>	<u>52,584,827</u>
Total net assets				
	<u>\$ 53,971,673</u>	<u>\$ 2,410,986</u>	<u>\$ (71,149)</u>	<u>\$ 56,311,510</u>

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

**Consolidating Schedule of Financial Position
June 30, 2023**

	The Association for Frontotemporal Degeneration	FTD Disorders Registry LLC	Eliminations	Consolidated Total
ASSETS				
Current assets:				
Cash and cash equivalents	\$ 288,666	\$ 269,495	\$ -	\$ 558,161
Accounts receivable	16,691	-	(16,691)	-
Pledges receivable	2,123,334	200,000	-	2,323,334
Governmental grants receivable	-	76,330	-	76,330
Investments	41,012,688	1,370,986	-	42,383,674
Prepaid expenses	148,697	1,188	-	149,885
	<u>43,590,076</u>	<u>1,917,999</u>	<u>(16,691)</u>	<u>45,491,384</u>
Pledges receivable, net of current portion and discount	3,222,219	-	-	3,222,219
Software and equipment, net of accumulated depreciation of \$63,665	33,661	125,500	-	159,161
Operating lease right-of-use asset	598,326	-	-	598,326
Security deposit	26,063	-	-	26,063
	<u>\$ 47,470,345</u>	<u>\$ 2,043,499</u>	<u>\$ (16,691)</u>	<u>\$ 49,497,153</u>
LIABILITIES				
Current liabilities:				
Accounts payable and accrued expenses	\$ 496,632	\$ 116,119	\$ (16,691)	\$ 596,060
Deferred revenues	198,744	-	-	198,744
Research grants payable	629,791	-	-	629,791
Current portion of operating lease liability	170,496	-	-	170,496
	<u>1,495,663</u>	<u>116,119</u>	<u>(16,691)</u>	<u>1,595,091</u>
Research grants payable	422,387	-	-	422,387
Long term operating lease liability	497,331	-	-	497,331
	<u>2,415,381</u>	<u>116,119</u>	<u>(16,691)</u>	<u>2,514,809</u>
NET ASSETS				
Net assets without donor restrictions:				
Undesignated	34,732,656	1,927,380	-	36,660,036
Board-designated	2,178,649	-	-	2,178,649
	<u>36,911,305</u>	<u>1,927,380</u>	<u>-</u>	<u>38,838,685</u>
Net assets with donor restrictions	8,143,659	-	-	8,143,659
	<u>45,054,964</u>	<u>1,927,380</u>	<u>-</u>	<u>46,982,344</u>
	<u>\$ 47,470,345</u>	<u>\$ 2,043,499</u>	<u>\$ (16,691)</u>	<u>\$ 49,497,153</u>

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

**Consolidating Schedule of Activities
Year Ended June 30, 2024**

	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	\$ 4,473,638	\$ 5,924,786	\$ 10,398,424	\$ 651,743	\$ 73,300	\$ 725,043	\$ (250,000)	\$ 4,875,381	\$ 5,998,086	\$ 10,873,467
Government grants	-	-	-	73,300	-	73,300	-	73,300	-	73,300
Other income	217,177	-	217,177	148,100	-	148,100	(166,500)	198,777	-	198,777
In-kind contributions	77,993	-	77,993	80,819	-	80,819	-	158,812	-	158,812
Special event revenue	2,059,742	-	2,059,742	-	-	-	-	2,059,742	-	2,059,742
Less: cost of direct benefit to donors	(174,240)	-	(174,240)	-	-	-	-	(174,240)	-	(174,240)
Net assets released from restrictions	4,520,615	(4,520,615)	-	-	-	-	-	4,520,615	(4,520,615)	-
	11,174,925	1,404,171	12,579,096	953,962	73,300	1,027,262	(416,500)	11,712,387	1,477,471	13,189,858
Expenses:										
Program services:										
Awareness and advocacy	2,871,133	-	2,871,133	-	-	-	-	2,871,133	-	2,871,133
Education and support	2,170,006	-	2,170,006	-	-	-	-	2,170,006	-	2,170,006
Research	4,887,316	-	4,887,316	-	-	-	(250,000)	4,637,316	-	4,637,316
FTD Registry	-	-	-	798,934	-	798,934	-	798,934	-	798,934
Total program services	9,928,455	-	9,928,455	798,934	-	798,934	(250,000)	10,477,389	-	10,477,389
Supporting services:										
Management and general	543,169	-	543,169	237,178	-	237,178	(166,500)	613,847	-	613,847
Fundraising	1,335,076	-	1,335,076	-	-	-	-	1,335,076	-	1,335,076
Total supporting services	1,878,245	-	1,878,245	237,178	-	237,178	(166,500)	1,948,923	-	1,948,923
	11,806,700	-	11,806,700	1,036,112	-	1,036,112	(416,500)	12,426,312	-	12,426,312
Change in net assets before other income	(631,775)	1,404,171	772,396	(82,150)	73,300	(8,850)	-	(713,925)	1,477,471	763,546
Other income:										
Investment income, net	4,753,783	-	4,753,783	85,154	-	85,154	-	4,838,937	-	4,838,937
Change in net assets	\$ 4,122,008	\$ 1,404,171	\$ 5,526,179	\$ 3,004	\$ 73,300	\$ 76,304	\$ -	\$ 4,125,012	\$ 1,477,471	\$ 5,602,483

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

**Consolidating Schedule of Activities
Year Ended June 30, 2023**

	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	\$ 4,433,673	\$ 2,532,930	\$ 6,966,603	\$ 1,356,540	\$ -	\$ 1,356,540	\$ (550,000)	\$ 5,240,213	\$ 2,532,930	\$ 7,773,143
Government grants	-	-	-	223,260	-	223,260	-	223,260	-	223,260
Other income	43,029	-	43,029	20,982	-	20,982	(38,428)	25,583	-	25,583
In-kind contributions	69,044	-	69,044	110,783	-	110,783	(39,346)	140,481	-	140,481
Special event revenue	1,982,084	-	1,982,084	-	-	-	-	1,982,084	-	1,982,084
Less: cost of direct benefit to donors	(178,807)	-	(178,807)	-	-	-	-	(178,807)	-	(178,807)
Net assets released from restrictions	2,439,908	(2,439,908)	-	85,000	(85,000)	-	-	2,524,908	(2,524,908)	-
	<u>8,788,931</u>	<u>93,022</u>	<u>8,881,953</u>	<u>1,796,565</u>	<u>(85,000)</u>	<u>1,711,565</u>	<u>(627,774)</u>	<u>9,957,722</u>	<u>8,022</u>	<u>9,965,744</u>
Expenses:										
Program services:										
Awareness and advocacy	2,292,337	-	2,292,337	-	-	-	-	2,292,337	-	2,292,337
Education and support	2,131,764	-	2,131,764	-	-	-	-	2,131,764	-	2,131,764
Research	3,454,814	-	3,454,814	-	-	-	(550,000)	2,904,814	-	2,904,814
FTD Registry	-	-	-	806,578	-	806,578	-	806,578	-	806,578
Total program services	<u>7,878,915</u>	<u>-</u>	<u>7,878,915</u>	<u>806,578</u>	<u>-</u>	<u>806,578</u>	<u>(550,000)</u>	<u>8,135,493</u>	<u>-</u>	<u>8,135,493</u>
Supporting services:										
Management and general	730,661	-	730,661	63,214	-	63,214	(77,774)	716,101	-	716,101
Fundraising	1,363,135	-	1,363,135	-	-	-	-	1,363,135	-	1,363,135
Total supporting services	<u>2,093,796</u>	<u>-</u>	<u>2,093,796</u>	<u>63,214</u>	<u>-</u>	<u>63,214</u>	<u>(77,774)</u>	<u>2,079,236</u>	<u>-</u>	<u>2,079,236</u>
	<u>9,972,711</u>	<u>-</u>	<u>9,972,711</u>	<u>869,792</u>	<u>-</u>	<u>869,792</u>	<u>(627,774)</u>	<u>10,214,729</u>	<u>-</u>	<u>10,214,729</u>
Change in net assets before other income	(1,183,780)	93,022	(1,090,758)	926,773	(85,000)	841,773	-	(257,007)	8,022	(248,985)
Other income:										
Investment income, net	3,576,147	-	3,576,147	-	-	-	-	3,576,147	-	3,576,147
Change in net assets	<u>\$ 2,392,367</u>	<u>\$ 93,022</u>	<u>\$ 2,485,389</u>	<u>\$ 926,773</u>	<u>\$ (85,000)</u>	<u>\$ 841,773</u>	<u>\$ -</u>	<u>\$ 3,319,140</u>	<u>\$ 8,022</u>	<u>\$ 3,327,162</u>

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

**Schedule of Functional Expenses – The Association for Frontotemporal Degeneration
Year Ended June 30, 2024**

	Program Services				Supporting Services			Total
	Awareness and Advocacy	Education and Support	Research	Subtotal	Management and General	Fundraising	Subtotal	
Salaries and wages	\$ 1,540,705	\$ 992,454	\$ 1,006,372	\$ 3,539,531	\$ 298,517	\$ 695,327	\$ 993,844	\$ 4,533,375
Payroll taxes and related benefits	302,370	195,803	195,004	693,177	58,207	139,621	197,828	891,005
Advertising	162,297	-	-	162,297	-	-	-	162,297
Bank and credit card processing fees	173	34	454	661	1,056	57,441	58,497	59,158
Conferences and meetings - facilities and other costs	18,075	290,392	426,430	734,897	11,255	670	11,925	746,822
Depreciation	2,800	592	3,119	6,511	774	1,821	2,595	9,106
Dues and subscriptions	7,104	1,767	208,505	217,376	4,792	3,505	8,297	225,673
Education - training	8,702	6,995	1,221	16,918	10,778	6,888	17,666	34,584
Equipment	8,652	5,989	5,643	20,284	3,781	-	3,781	24,065
Events	134,572	-	-	134,572	-	32,465	32,465	167,037
Grants awarded	-	241,506	2,684,999	2,926,505	-	-	-	2,926,505
Insurance	10,865	7,761	4,890	23,516	1,872	6,078	7,950	31,466
Management information systems	193,698	119,788	81,564	395,050	24,008	73,183	97,191	492,241
Office and supplies	10,496	7,956	3,546	21,998	11,041	7,420	18,461	40,459
Postage and shipping	17,899	8,421	1,283	27,603	1,752	15,771	17,523	45,126
Printing and copying	78,533	9,421	7,969	95,923	616	35,743	36,359	132,282
Professional fees	240,981	82,910	118,073	441,964	85,519	144,784	230,303	672,267
Recruitment	796	1,385	399	2,580	3,674	1,603	5,277	7,857
Rent	75,116	65,554	37,238	177,908	18,620	44,905	63,525	241,433
Telecommunications data	11,402	27,067	6,024	44,493	-	5,541	5,541	50,034
Travel	45,897	104,211	94,583	244,691	6,907	62,310	69,217	313,908
Total expenses included in the expenses section on the consolidated statements of activities	2,871,133	2,170,006	4,887,316	9,928,455	543,169	1,335,076	1,878,245	11,806,700
Plus expenses included with revenue section on the consolidated statements of activities:								
Cost of direct benefits to donors:								
Food, beverage and greens fees	-	-	-	-	-	174,240	174,240	174,240
Total expenses	\$ 2,871,133	\$ 2,170,006	\$ 4,887,316	\$ 9,928,455	\$ 543,169	\$ 1,509,316	\$ 2,052,485	\$ 11,980,940

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

**Schedule of Functional Expenses – The Association for Frontotemporal Degeneration
Year Ended June 30, 2023**

	Program Services				Supporting Services			Total
	Awareness and Advocacy	Education and Support	Research	Subtotal	Management and General	Fundraising	Subtotal	
Salaries and wages	\$ 1,174,272	\$ 919,782	\$ 867,548	\$ 2,961,602	\$ 266,501	\$ 762,323	\$ 1,028,824	\$ 3,990,426
Payroll taxes and related benefits	232,354	186,890	175,426	594,670	39,873	153,318	193,191	787,861
Advertising	177,819	-	-	177,819	-	-	-	177,819
Bank and credit card processing fees	-	75	173	248	1,658	50,261	51,919	52,167
Conferences and meetings	27,198	370,184	129,414	526,796	45,962	-	45,962	572,758
Depreciation	2,554	3,192	1,915	7,661	2,554	2,554	5,108	12,769
Dues and subscriptions	4,829	1,293	7,382	13,504	4,969	3,093	8,062	21,566
Education - training	10,569	11,752	7,870	30,191	60,953	15,920	76,873	107,064
Equipment	-	-	85	85	35,221	2,000	37,221	37,306
Events	124,356	-	-	124,356	4,501	164,068	168,569	292,925
Grants awarded	95,023	324,435	2,056,341	2,475,799	-	-	-	2,475,799
Insurance	5,770	10,097	4,327	20,194	5,657	4,327	9,984	30,178
Management information systems	205,128	161,103	98,008	464,239	90,059	98,410	188,469	652,708
Office and supplies	4,461	3,106	851	8,418	22,500	1,048	23,548	31,966
Postage and shipping	10,510	2,268	734	13,512	3,998	16,069	20,067	33,579
Printing and copying	57,036	1,699	4,033	62,768	912	26,375	27,287	90,055
Recruitment	67,327	21,071	20,148	108,546	100,200	17,798	117,998	226,544
Professional fees	13,566	1,106	394	15,066	1,873	852	2,725	17,791
Rent	45,267	79,217	33,950	158,434	35,630	33,950	69,580	228,014
Telecommunications and data	5,483	27,504	4,145	37,132	5,868	3,695	9,563	46,695
Travel	28,815	6,990	42,070	77,875	1,772	7,074	8,846	86,721
Total expenses included in the expenses section on the consolidated statements of activities	2,292,337	2,131,764	3,454,814	7,878,915	730,661	1,363,135	2,093,796	9,972,711
Plus expenses included with revenue section on the consolidated statements of activities:								
Cost of direct benefits to donors:								
Food, beverage and greens fees	-	-	-	-	-	178,807	178,807	178,807
Total expenses	\$ 2,292,337	\$ 2,131,764	\$ 3,454,814	\$ 7,878,915	\$ 730,661	\$ 1,541,942	\$ 2,272,603	\$ 10,151,518

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

**Schedule of Functional Expenses – FTD Disorders Registry LLC
Year Ended June 30, 2024**

	<u>Program Services</u>	<u>General and Administrative</u>	<u>Total Expenses</u>
Salaries and wages	\$ 428,930	\$ 14,534	\$ 443,464
Payroll taxes and related benefits	91,825	2,525	94,350
Advertising	6,094	-	6,094
Bank and credit card processing fees	27	784	811
Conferences and meetings	-	2,218	2,218
Depreciation	11,429	-	11,429
Dues and subscriptions	-	85	85
Education - training	422	-	422
Insurance	-	6,250	6,250
Management information systems	176,550	4,704	181,254
Office and supplies	252	229	481
Postage and shipping	-	13	13
Printing and copying	-	77	77
Professional fees	74,846	196,095	270,941
Recruitment	402	782	1,184
Telecommunications and data	1,391	2,200	3,591
Travel	6,766	6,682	13,448
	<u>\$ 798,934</u>	<u>\$ 237,178</u>	<u>\$ 1,036,112</u>
Total expenses	<u>\$ 798,934</u>	<u>\$ 237,178</u>	<u>\$ 1,036,112</u>

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

**Schedule of Functional Expenses – FTD Disorders Registry LLC
Year Ended June 30, 2023**

	<u>Program Services</u>	<u>General and Administrative</u>	<u>Total Expenses</u>
Salaries and wages	\$ 368,676	\$ 38,680	\$ 407,356
Payroll taxes and related benefits	89,127	4,232	93,359
Advertising	2,876	-	2,876
Bank and credit card processing fees	30	676	706
Conferences and meetings	115	-	115
Dues and subscriptions	200	-	200
Education - training	-	50	50
Insurance	-	5,679	5,679
Management information systems	204,008	-	204,008
Office and supplies	-	1,741	1,741
Postage and shipping	163	382	545
Printing and copying	-	103	103
Professional fees	130,362	-	130,362
Recruitment	-	3,775	3,775
Rent	-	2,743	2,743
Telecommunications and data	-	4,462	4,462
Travel	11,021	691	11,712
	<u>11,021</u>	<u>691</u>	<u>11,712</u>
Total expenses	<u>\$ 806,578</u>	<u>\$ 63,214</u>	<u>\$ 869,792</u>