

THE ASSOCIATION FOR  
FRONTOTEMPORAL DEGENERATION  
AND  
FTD DISORDERS REGISTRY LLC

FINANCIAL STATEMENTS

JUNE 30, 2023 and 2022  
(with consolidating supplementary information)

# THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

## Contents

	<u>Page</u>
<b>Independent Auditors' Report</b>	1 - 2
<b>Consolidated Financial Statements</b>	
Statements of financial position as of June 30, 2023 and 2022	3
Statements of activities for the years ended June 30, 2023 and 2022	4
Statements of changes in net assets for the years ended June 30, 2023 and 2022	5
Statements of functional expenses for the years ended June 30, 2023 and 2022	6 - 7
Statements of cash flows for the years ended June 30, 2023 and 2022	8
Notes to financial statements	9 - 23
<b>Supplementary Information</b>	
Consolidating schedules of financial position as of June 30, 2023 and 2022	24 - 25
Consolidating schedules of activities for the year ended June 30, 2023 and 2022	26 - 27
Schedules of functional expenses – The Association for Frontotemporal Degeneration for the years ended June 30, 2023 and 2022	28 - 29
Schedules of functional expenses – FTD Disorders Registry, LLC for the years ended June 30, 2023 and 2022	30 - 31

## **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 (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, 2023 and 2022, 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, 2023 and 2022, 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 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 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 25, 2023



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

**Consolidated Statements of Financial Position**

	June 30,	
	<u>2023</u>	<u>2022</u>
<b>ASSETS</b>		
Current assets:		
Cash and cash equivalents	\$ 558,161	\$ 1,161,722
Accounts receivable	-	726
Pledges receivable	2,323,334	2,677,367
Governmental grants receivable	76,330	61,248
Investments	42,383,674	36,665,426
Prepaid expenses	149,885	91,431
	<u>45,491,384</u>	<u>40,657,920</u>
Pledges receivable, net of current portion and discount	3,222,219	5,188,090
Software and equipment, net of accumulated depreciation of \$245,537 in 2023 and \$232,768 in 2022	159,161	46,430
Operating lease right-of-use asset	598,326	-
Security deposit	26,063	26,063
	<u>\$ 49,497,153</u>	<u>\$ 45,918,503</u>
<b>LIABILITIES</b>		
Current liabilities:		
Accounts payable and accrued expenses	\$ 596,060	360,084
Deferred revenues	198,744	30,538
Research grants payable	629,791	1,307,983
Current portion of operating lease liability	170,496	-
	<u>1,595,091</u>	<u>1,698,605</u>
Research grants payable	422,387	487,676
Deferred rent	-	77,040
Long-term operating lease liability	497,331	-
	<u>2,514,809</u>	<u>2,263,321</u>
Commitments and contingencies		
<b>NET ASSETS</b>		
Net assets without donor restrictions:		
Undesignated	35,696,345	32,177,241
Board-designated	2,178,649	2,842,000
	<u>37,874,994</u>	<u>35,019,241</u>
Net assets with donor restrictions	<u>8,143,659</u>	<u>8,093,137</u>
Total net assets controlling interest	46,018,653	43,112,378
Noncontrolling interest	<u>963,691</u>	<u>542,804</u>
Total net assets	<u>46,982,344</u>	<u>43,655,182</u>
	<u>\$ 49,497,153</u>	<u>\$ 45,918,503</u>

See notes to financial statements.

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

**Consolidated Statements of Activities**

	Year Ended June 30,					
	2023			2022		
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total
<b>Revenue and support:</b>						
Contributions	\$ 5,240,213	\$ 2,532,930	\$ 7,773,143	\$ 7,708,779	\$ 2,532,878	\$ 10,241,657
Government grants	223,260	-	223,260	220,600	-	220,600
Other income	25,583	-	25,583	4,537	-	4,537
Contributed services	140,481	-	140,481	113,493	-	113,493
Special event revenue, net of cost of direct benefits to donors of \$178,807 in 2023 and \$170,259 in 2022	1,803,277	-	1,803,277	2,150,504	-	2,150,504
Net assets released from restrictions	2,524,908	(2,524,908)	-	3,153,161	(3,153,161)	-
	<u>9,957,722</u>	<u>8,022</u>	<u>9,965,744</u>	<u>13,351,074</u>	<u>(620,283)</u>	<u>12,730,791</u>
<b>Expenses:</b>						
Program services:						
Awareness and advocacy	2,292,337	-	2,292,337	1,589,047	-	1,589,047
Education and support	2,131,764	-	2,131,764	1,758,969	-	1,758,969
Research	2,904,814	-	2,904,814	3,675,017	-	3,675,017
FTD Registry	806,578	-	806,578	739,769	-	739,769
Total program services	<u>8,135,493</u>	<u>-</u>	<u>8,135,493</u>	<u>7,762,802</u>	<u>-</u>	<u>7,762,802</u>
Supporting services:						
Management and general	716,101	-	716,101	616,045	-	616,045
Fundraising	1,363,135	-	1,363,135	1,055,827	-	1,055,827
Total supporting services	<u>2,079,236</u>	<u>-</u>	<u>2,079,236</u>	<u>1,671,872</u>	<u>-</u>	<u>1,671,872</u>
	<u>10,214,729</u>	<u>-</u>	<u>10,214,729</u>	<u>9,434,674</u>	<u>-</u>	<u>9,434,674</u>
<b>Change in net assets before other income (loss)</b>	<b>(257,007)</b>	<b>8,022</b>	<b>(248,985)</b>	<b>3,916,400</b>	<b>(620,283)</b>	<b>3,296,117</b>
<b>Other income (loss):</b>						
Investment income (loss), net	3,576,147	-	3,576,147	(3,618,583)	-	(3,618,583)
<b>Change in net assets</b>	<b>3,319,140</b>	<b>8,022</b>	<b>3,327,162</b>	<b>297,817</b>	<b>(620,283)</b>	<b>(322,466)</b>
<b>Change in net assets attributable to the noncontrolling interest</b>	<b>463,387</b>	<b>(42,500)</b>	<b>420,887</b>	<b>(45,799)</b>	<b>42,500</b>	<b>(3,299)</b>
<b>Change in net assets attributable to the controlling interest</b>	<b>\$ 2,855,753</b>	<b>\$ 50,522</b>	<b>\$ 2,906,275</b>	<b>\$ 343,616</b>	<b>\$ (662,783)</b>	<b>\$ (319,167)</b>

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, 2023 and 2022**

	<b>Controlling Interest</b>		<b>Noncontrolling Interest</b>		<b>Total</b>
	<b>Net Assets Without Donor Restrictions</b>	<b>Net Assets With Donor Restrictions</b>	<b>Net Assets Without Donor Restrictions</b>	<b>Net Assets With Donor Restrictions</b>	
Net assets at July 1, 2022	\$ 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	35,019,241	8,093,137	500,304	42,500	43,655,182
<b>Change in net assets</b>	<b><u>2,855,753</u></b>	<b><u>50,522</u></b>	<b><u>463,387</u></b>	<b><u>(42,500)</u></b>	<b><u>3,327,162</u></b>
<b>Net assets at June 30, 2023</b>	<b><u>\$ 37,874,994</u></b>	<b><u>\$ 8,143,659</u></b>	<b><u>\$ 963,691</u></b>	<b><u>\$ -</u></b>	<b><u>\$ 46,982,344</u></b>

**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
<b>Expenses:</b>									
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	88,174	69,825	66,124	28,831	252,954	21,296	57,933	79,229	332,183
Employee benefits	144,180	117,065	109,302	60,296	430,843	22,809	95,385	118,194	549,037
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	\$ 2,292,337	\$ 2,131,764	\$ 2,904,814	\$ 806,578	\$ 8,135,493	\$ 716,101	\$ 1,541,942	\$ 2,258,043	\$ 10,393,536

See notes to financial statements.



**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	
<b>Expenses:</b>									
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 expenses section on the consolidated statements of activities	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 section on the consolidated statements of activities									
Cost of direct benefits to donors									
Food, beverage and greens fees	-	-	-	-	-	-	170,259	170,259	170,259
Total expenses	<u>\$ 1,589,047</u>	<u>\$ 1,758,969</u>	<u>\$ 3,675,017</u>	<u>\$ 739,769</u>	<u>\$ 7,762,802</u>	<u>\$ 616,045</u>	<u>\$ 1,226,086</u>	<u>\$ 1,842,131</u>	<u>\$ 9,604,933</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>2023</u>	<u>2022</u>
<b>Cash flows from operating activities:</b>		
Change in net assets	\$ 3,327,162	\$ (322,466)
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation	12,769	45,878
Deferred rent	-	(3,389)
Amortization of operating lease right-of-use asset	145,530	-
Amortization of discount on contributions receivable	(109,130)	(109,677)
Donated securities	(161,062)	(3,052,077)
Proceeds from sale of donated securities	159,327	2,968,193
Realized and unrealized (gain) loss on investments	(2,471,249)	3,950,531
(Increase) decrease in assets:		
Accounts receivable	726	(726)
Pledges receivable	2,429,034	1,006,707
Governmental grants receivable	(15,082)	(19,357)
Prepaid expenses	(58,454)	(28,891)
Increase (decrease) in liabilities:		
Accounts payable and accrued expenses	235,976	76,256
Deferred revenues	168,206	(45,396)
Research grants payable	(743,481)	299,463
Operating lease liability	(153,069)	-
	<u>2,767,203</u>	<u>4,765,049</u>
<b>Net cash provided by operating activities</b>		
<b>Cash flows from investing activities:</b>		
Proceeds from sale of investments	7,362,086	21,721,364
Purchase of investments	(10,607,350)	(26,537,544)
Purchase of equipment	(125,500)	(21,075)
	<u>(3,370,764)</u>	<u>(4,837,255)</u>
<b>Net cash used in investing activities</b>		
<b>Net decrease in cash and cash equivalents</b>	<b>(603,561)</b>	<b>(72,206)</b>
Cash and cash equivalents at beginning of year	<u>1,161,722</u>	<u>1,233,928</u>
<b>Cash and cash equivalents at end of year</b>	<u><b>\$ 558,161</b></u>	<u><b>\$ 1,161,722</b></u>

See notes to financial statements.

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

## **Notes to Financial Statements June 30, 2023 and 2022**

### **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, 2023 and 2022

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### [1] Principles of consolidation:

The accompanying 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 the FTD Disorders Registry LLC as of both June 30, 2023 and 2022 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. As of July 1, 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, 2023 and 2022 was \$1,800,000 and \$2,350,000, 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, 2023 and 2022 was \$378,649 and 492,000, 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 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.

# THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

## Notes to Financial Statements June 30, 2023 and 2022

### 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 consolidated financial statements.

#### [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, 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.

#### [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, 2023 and 2022, 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, 2023 or 2022.

#### [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 Financial Statements June 30, 2023 and 2022

### 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, 2023 and 2022, 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, 2023 and 2022 was \$12,769 and \$45,879, respectively.

#### [13] Revenue recognition:

##### *Contributions*

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

The Organization recognizes unconditional contributions when cash, securities or other assets, or an unconditional promise to give is received, and are recorded after discounting to the present value of the expected future cash flows. 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, 2023 and 2022. 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, 2023 or 2022 that will be recognized in subsequent years as costs are incurred and service requirements are met.

# THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

## Notes to Financial Statements June 30, 2023 and 2022

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

#### [13] Revenue recognition: (continued)

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, 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, 2023 were \$140,000 and are included in deferred revenue as of June 30, 2023.

#### *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, 2023 and 2022, there were conditional contributions associated with special events of \$58,744 and \$30,538, respectively, which is included in deferred revenue on the consolidated statements of financial position.

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

**Notes to Financial Statements  
June 30, 2023 and 2022**

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

**[14] 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. Contributed services for the years ended June 30, 2023 and 2022 are as follows:

		<b>Year Ended June 30, 2023</b>			
		<b>Program Services</b>	<b>Management and General</b>	<b>Fundraising</b>	<b>Total</b>
Legal		<u>\$ 115,953</u>	<u>\$ 24,528</u>	<u>\$ -</u>	<u>\$ 140,481</u>
		<b>Year Ended June 30, 2022</b>			
		<b>Program Services</b>	<b>Management and General</b>	<b>Fundraising</b>	<b>Total</b>
IT services		\$ 1,000	\$ -	\$ -	\$ 1,000
Legal		<u>90,434</u>	<u>22,059</u>	<u>-</u>	<u>112,493</u>
		<u>\$ 91,434</u>	<u>\$ 22,059</u>	<u>\$ -</u>	<u>\$ 113,493</u>

**[15] Leases:**

The Organization determines if an arrangement is a lease at inception.

Operating leases are recorded as operating right-of use ("ROU") assets and operating lease liabilities (current portion and long-term portion) on the accompanying statements of financial position. Operating lease ROU assets and the related lease liabilities are recognized based on the present value of the future minimum lease payments over the lease term at commencement date. The operating lease ROU assets also include lease incentives and initial direct costs incurred. For operating leases, interest on the lease liability and the amortization of ROU assets result in straight-line rent expense over the lease term.

Leases may include options to extend or terminate the lease, which are included in the ROU operating lease assets and operating lease liability when they are reasonably certain of exercise. Operating lease expense associated with minimum lease payments is recognized in a straight-line basis over the lease term. When additional payments are based on usage or vary based on other factors, they are considered variable lease payments and are excluded from the measurement of the ROU asset and lease liability. These payments are recognized as an expense in the period in which the related obligation was incurred.



# THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION AND FTD DISORDERS REGISTRY LLC

## Notes to Financial Statements June 30, 2023 and 2022

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

#### [16] Adoption of new accounting pronouncements:

In February 2016, the Financial Accounting Standards Board ("FASB") issued Accounting Standards Update ("ASU") 2016-02, *Leases (Topic 842)*. The ASU's core principle is to increase transparency and comparability among organizations by requiring the recognition of ROU assets and lease liabilities on the statement of financial position and disclosing key information. Most prominent among the changes in the standard is the recognition of ROU assets and lease liabilities by lessees for those leases classified as operating leases. Under the standard, disclosures are required to meet the objective of enabling users of financial statements to assess the amount, timing, and uncertainty of cash flows arising from leases.

AFTD adopted the standard effective January 1, 2022 and recognized and measured leases existing July 1, 2022, the beginning of the period of adoption. Lease disclosures for the year ended June 30, 2022 are made under prior lease guidance in FASB Accounting Standards Codification ("ASC") 840. Operating leases were recorded on a straight-line basis over the term of the lease. Accordingly, AFTD applied the guidance to each lease that had commenced as of the adoption date and also elected a package of practical expedients, which included the following: no requirement to reassess (a) whether any expired or existing contracts are, or contain, leases, (b) the lease classification for any expired or existing leases, and (c) the recognition requirements for initial direct costs for any existing leases. AFTD also elected a practical expedient to account for lease and non-lease components as a single lease component. AFTD excluded short-term leases having initial terms of twelve months or less from the new guidance as an accounting policy election and recognizes rent expense for such leases on a straight-line basis over the lease term. In calculating the related lease liabilities at the time of adoption, AFTD utilized historical experience when determining the noncancelable portion of the lease term and elected to use the risk-free rate commensurate with the remaining lease term as the discount rate as of the date of adoption.

As a result of the adoption of the new lease accounting, AFTD recognized on July 1, 2022 an operating lease liability of \$820,896, which represents the present value of the remaining operating lease payments, discounted using the risk-free rate of 1.8%, and a ROU asset of \$743,856, which represents the operating lease liability of \$820,896 adjusted for deferred rent of \$77,040.

The standard had a material impact on AFTD's statements of financial position but did not have an impact on its statements of activities or cash flows. The most significant impact was the recognition of ROU assets and liabilities for operating leases.

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

**Notes to Financial Statements  
June 30, 2023 and 2022**

**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, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
Current financial assets:		
Cash and cash equivalents	\$ 558,161	\$ 1,161,722
Accounts receivable	-	726
Pledges receivable	2,323,334	2,677,367
Governmental grants receivable	76,330	61,248
Investments	<u>42,383,674</u>	<u>36,665,426</u>
Total current financial assets at year-end	<u>45,341,499</u>	<u>40,566,489</u>
Less amounts not available to be used within one year:		
Net assets with donor restrictions subject to expenditures for specified purposes	(118,102)	(519,943)
Board-designated for specific purpose	<u>(2,178,649)</u>	<u>(2,842,000)</u>
	<u>(2,296,751)</u>	<u>(3,361,943)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 43,044,748</u>	<u>\$ 37,204,546</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, 2023 and 2022 are as follows:

	<u>2023</u>	<u>2022</u>
Checking accounts	\$ 558,161	\$ 741,875
Savings accounts	-	419,847
	<u>\$ 558,161</u>	<u>\$ 1,161,722</u>

Prior to being closed during the year ended June 30, 2023, savings accounts earned interest at a rate of 0.01% per annum. 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 Financial Statements  
June 30, 2023 and 2022**

**NOTE E - INVESTMENTS**

Investments consist of the following as of June 30, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
Investments:		
Common stock	\$ 19,074,738	\$ 12,663,347
Fixed income ETFs	2,249,447	3,311,868
Fixed income funds	1,090,012	-
Corporate bonds	3,431,885	1,171,237
Municipal bonds	115,964	118,315
Treasury bonds	1,320,212	691,816
Mutual funds	<u>7,116,573</u>	<u>10,450,826</u>
Investments measured at fair value	<u>34,398,831</u>	28,407,409
Money market funds	<u>7,984,843</u>	<u>8,258,017</u>
Total investments	<u>\$ 42,383,674</u>	<u>\$ 36,665,426</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 Financial Statements  
June 30, 2023 and 2022**

**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, 2023 and 2022:

**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
Total investment assets at fair value	<u>\$ 29,530,770</u>	<u>\$ 4,868,061</u>	<u>\$ -</u>	<u>\$ 34,398,831</u>

**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>

**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, 2023 and 2022, 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, 2023 and 2022**

**NOTE G - GOVERNMENTAL GRANTS AND PLEDGES RECEIVABLE**

Governmental grants and pledges receivable outstanding as of June 30, 2023 and 2022 are summarized as follows:

	<b>2023</b>	
	<b>Pledges Receivable</b>	<b>Governmental Grants Receivable</b>
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	<u>\$ 5,545,553</u>	<u>\$ 76,330</u>
	<b>2022</b>	
	<b>Pledges Receivable</b>	<b>Governmental Grants Receivable</b>
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	<u>\$ 7,865,457</u>	<u>\$ 61,248</u>

Pledges receivable are unconditional promises to give and are presented at net present value using discount factors ranging from 1.42% to 2.71% in both 2023 and 2022, 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, 2023 and 2022, 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 \$4 million and \$5 million was not recorded in the consolidated statements of financial position as of June 30, 2023 and 2022, respectively, because the conditions for the commitment have not been met.

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

**Notes to Financial Statements  
June 30, 2023 and 2022**

**NOTE I - RESEARCH GRANTS PAYABLE**

Research grants payable as of June 30, 2023 and 2022 are summarized as follows:

	<u>2023</u>	<u>2022</u>
Research grants payable expected to be paid:		
Less than one year	\$ 629,791	\$ 1,307,983
One to five years	<u>422,387</u>	<u>487,676</u>
Total research grants payable	<u>\$ 1,052,178</u>	<u>\$ 1,795,659</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, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
<b>Subject to passage of time:</b>		
Promises to give that are not restricted by donors	<u>\$ 5,103,470</u>	<u>\$ 6,031,907</u>
<b>Subject to expenditures for specified purpose:</b>		
Research, Holloway Family Fund	1,945,622	1,418,776
Research, other	574,940	75,000
FTDDR Platform upgrade	-	85,000
Genetics initiatives	24,333	-
Support and education	240,000	13,200
Awareness:	5,011	5,011
Promises to give, the proceeds from which have been restricted by donors for:		
Research, FTD Biomarkers	132,181	245,279
Research, FTD/ALS	<u>118,102</u>	<u>261,464</u>
	<u>3,040,189</u>	<u>2,103,730</u>
	<u>\$ 8,143,659</u>	<u>\$ 8,135,637</u>

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

**Notes to Financial Statements  
June 30, 2023 and 2022**

**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, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
<b>Satisfaction of time restriction:</b>		
Funds received	<b>\$ 1,554,167</b>	\$ 1,075,000
<b>Satisfaction of purpose restriction:</b>		
Research, Holloway Family Fund	<b>473,153</b>	1,047,791
Research, FTD Biomarkers	<b>113,098</b>	189,219
Research, Target ALS	<b>151,763</b>	756,151
Research, other	<b>60</b>	85,000
FTDDR Platform upgrade	<b>85,000</b>	-
Support and education	<b>72,000</b>	-
Genetic initiatives	<b>75,667</b>	-
	<b><u>\$ 2,524,908</u></b>	<b><u>\$ 3,153,161</u></b>

**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 the year ended June 30, 2023, relating to operating leases, consisting of ROU asset amortization and lease liability interest, is included in rent on the statements of functional expenses.

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

**Notes to Financial Statements  
June 30, 2023 and 2022**

**NOTE K - LEASE AGREEMENT (CONTINUED)**

The following maturity analysis of the annual undiscounted cash flows of the operating lease liability is as follows:

<u>Year Ending June 30,</u>	<u>Amount</u>
2024	\$ 170,496
2025	174,646
2026	178,796
2027	<u>167,556</u>
	691,494
Less: amount representing interest	<u>(23,667)</u>
	<u>\$ 667,827</u>

  

<u>Reported as of June 30, 2023</u>	<u>Operating Leases</u>
Current portion of lease liability	\$ 170,496
Lease Liability, net of current portion	<u>497,331</u>
Total	<u>\$ 667,827</u>

As of June 30, 2023, the operating lease ROU assets and operating lease liability related to the agreement were \$598,326 and \$667,827, respectively. The weighted average remaining lease term of the lease agreement is 3.92 years and weighted average discount rate is 1.8%. The total rent expense under the agreement, which includes a monthly operating expense assessment of \$5,783, was \$225,699 and \$228,201 for the years ended June 30, 2023 and 2022, respectively. The cash paid for amounts included in the measurement of lease liabilities was \$166,346.

**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, 2023 and 2022, there were \$48,215 and \$28,137, 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 2023, 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, 2023 and 2022, the employer match was \$113,989 and \$83,375, respectively.



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

## **Notes to Financial Statements June 30, 2023 and 2022**

### **NOTE N - RELATED PARTY TRANSACTIONS**

A Board member of AFTD is a substantial contributor for the years ended June 30, 2023 and 2022. Contributions, including promises to give, from this contributor for the years ended June 30, 2023 and 2022 were \$11,010 and \$3,020,150, respectively. In addition, the Board member is an officer of a foundation that is a substantial contributor to AFTD. Contributions from the foundation were \$-0- and \$850,000 for the years ended June 30, 2023 and 2022, respectively. Contributions receivable from the foundation were \$4,472,685 and \$6,580,919 as of June 30, 2023 and 2022, respectively.

An additional Board member of AFTD is also a substantial contributor to the Organization. Donations for the years ended June 30, 2023 and 2022 were \$1,015,505 and \$1,005,000, 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 \$600,000 and \$200,000 in contributions for the years ended June 30, 2023 and 2022, respectively. Contributions receivable were \$200,000 and \$-0- as of June 30, 2023 and 2022, 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 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.

### **NOTE P - SUBSEQUENT EVENTS**

The Organization has evaluated subsequent events through October 25, 2023, 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, 2023**

	<b>The Association for Frontotemporal Degeneration</b>	<b>FTD Disorders Registry LLC</b>	<b>Eliminations</b>	<b>Consolidated Total</b>
<b>ASSETS</b>				
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
Total current assets	<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 \$245,537	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>
<b>LIABILITIES</b>				
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
Total current liabilities	<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
Total liabilities	<u>2,415,381</u>	<u>116,119</u>	<u>16,691</u>	<u>2,514,809</u>
<b>NET ASSETS</b>				
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
Total net assets	<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 Financial Position  
June 30, 2022**

	<b>The Association for Frontotemporal Degeneration</b>	<b>FTD Disorders Registry LLC</b>	<b>Eliminations</b>	<b>Consolidated Total</b>
<b>ASSETS</b>				
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>
<b>LIABILITIES</b>				
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>
<b>NET ASSETS</b>				
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 Activities  
Year Ended June 30, 2023**

	The Association for Frontotemporal Degeneration			FTD Disorders Registry LLC			Eliminations	Consolidated Totals		
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total		Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Consolidated Total
<b>Revenue and support:</b>										
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>
<b>Expenses:</b>										
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>
<b>Change in net assets before other income</b>	(1,183,780)	93,022	(1,090,758)	926,773	(85,000)	841,773	-	(257,007)	8,022	(248,985)
<b>Other income:</b>										
Investment income, net	3,576,147	-	3,576,147	-	-	-	-	3,576,147	-	3,576,147
<b>Change in net assets</b>	<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**

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

	The Association for Frontotemporal Degeneration			FTD Disorders Registry LLC			Eliminations	Consolidated Totals		
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total		Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Consolidated Total
<b>Revenue and support:</b>										
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>
<b>Expenses:</b>										
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>
<b>Change in net assets before other income</b>	<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>
<b>Other income:</b>										
Investment loss, net	<u>(3,618,583)</u>	<u>-</u>	<u>(3,618,583)</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(3,618,583)</u>	<u>-</u>	<u>(3,618,583)</u>
<b>Change in net assets</b>	<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**

**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	88,174	69,825	66,124	224,123	20,268	57,933	78,201	302,324
Employee benefits	144,180	117,065	109,302	370,547	19,605	95,385	114,990	485,537
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
Professional fees	67,327	21,071	20,148	108,546	100,200	17,798	117,998	226,544
Recruitment	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 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
	<b>2,292,337</b>	<b>2,131,764</b>	<b>3,454,814</b>	<b>7,878,915</b>	<b>730,661</b>	<b>1,363,135</b>	<b>2,093,796</b>	<b>9,972,711</b>
Total expenses included in the expenses section on the consolidated statements of activities								
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
	<b>2,292,337</b>	<b>2,131,764</b>	<b>3,454,814</b>	<b>7,878,915</b>	<b>730,661</b>	<b>1,541,942</b>	<b>2,272,603</b>	<b>10,151,518</b>
Total expenses								

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

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

	Program Services				Supporting Services			Total
	Awareness and Advocacy	Education and Support	Research	Subtotal	Management and General	Fundraising	Subtotal	
Salaries and wages	\$ 609,376	\$ 851,165	\$ 736,285	\$ 2,196,826	\$ 183,639	\$ 513,952	\$ 697,591	\$ 2,894,417
Payroll taxes	45,669	63,379	54,936	163,984	13,521	38,722	52,243	216,227
Employee benefits	81,003	109,979	95,198	286,180	19,254	65,038	84,292	370,472
Advertising	127,360	-	-	127,360	-	-	-	127,360
Bank and credit card processing fees	37	393	155	585	811	40,269	41,080	41,665
Conferences and meetings	154,871	142,276	397,987	695,134	39,636	3	39,639	734,773
Depreciation	2,429	3,036	1,822	7,287	2,428	2,429	4,857	12,144
Dues and subscriptions	2,155	4,429	8,416	15,000	2,836	1,824	4,660	19,660
Education - training	5,070	8,863	3,855	17,788	5,815	14,161	19,976	37,764
Events	145,376	-	152	145,528	-	165,985	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	6,362	21,968
Management information systems	169,889	176,667	91,202	437,758	63,967	110,155	174,122	611,880
Office and supplies	10,274	4,790	1,777	16,841	63,986	1,717	65,703	82,544
Postage and shipping	16,659	5,326	1,107	23,092	2,411	7,650	10,061	33,153
Printing and copying	63,072	3,727	40	66,839	401	10,122	10,523	77,362
Professional fees	99,133	71,742	148,680	319,555	162,379	41,623	204,002	523,557
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	5,699	2,637	8,336	39,321
Travel	979	709	9,111	10,799	607	1,966	2,573	13,372
Total expenses included in the expenses 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	1,662,952	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, beverage and greens fees	-	-	-	-	-	170,259	170,259	170,259
Total expenses	<u>\$ 1,589,047</u>	<u>\$ 1,758,969</u>	<u>\$ 3,825,017</u>	<u>\$ 7,173,033</u>	<u>\$ 607,125</u>	<u>\$ 1,226,086</u>	<u>\$ 1,833,211</u>	<u>\$ 9,006,244</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	28,831	1,028	29,859
Employee benefits	60,296	3,204	63,500
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>

**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>