

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

Financial Statements

Years Ended December 31, 2023 and 2022



**LES  
TURNER  
ALS  
FOUNDATION**

**WIPFLI**

## **Independent Auditor's Report**

To the Board of Directors  
Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.  
Skokie, Illinois

### ***Opinion***

We have audited the financial statements of Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd. (the "Foundation"), a nonprofit organization, which comprise the statements of financial position as of December 31, 2023 and 2022, and the related statements of activities and change in net assets, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements referred to above present fairly, in all material respects, the financial position of Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd. as of December 31, 2023 and 2022, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America ("GAAP").

### ***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 Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd. 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.

### ***Responsibilities of Management for the Financial Statements***

Management is responsible for the preparation and fair presentation of the financial statements in accordance with GAAP, 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 Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.'s ability to continue as a going concern for one year after the date the financial statements are available to be issued.

## ***Auditor's 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 auditor's 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 Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.'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 Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.'s ability to continue as a going concern for a reasonable period of time.

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

A handwritten signature in black ink that reads "Wipfli LLP". The signature is written in a cursive, flowing style.

Wipfli LLP

July 1, 2024

Lincolnshire, Illinois

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Statements of Financial Position

<i>December 31,</i>	2023	2022
<b>Assets</b>		
Current assets:		
Cash and cash equivalents	\$ 2,058,972	\$ 945,581
Certificates of deposit	124,165	1,725,801
Contributions receivable	162,726	103,899
Other receivable	97,333	97,333
Prepaid expenses	95,433	72,724
Total current assets	<u>2,538,629</u>	<u>2,945,338</u>
Property and equipment at cost:		
Leasehold improvements	55,777	55,777
Furniture, fixtures, and equipment	216,767	316,987
Right of use assets - operating	605,141	691,482
Total property and equipment at cost	<u>877,685</u>	<u>1,064,246</u>
Less accumulated depreciation and amortization	<u>247,258</u>	<u>342,086</u>
	<u>630,427</u>	<u>722,160</u>
Other assets:		
Intangible assets, net	110,450	89,382
Deposits	7,254	7,254
Total other assets	<u>117,704</u>	<u>96,636</u>
Total assets	<u>\$ 3,286,760</u>	<u>\$ 3,764,134</u>
<b>Liabilities and Net Assets</b>		
Current liabilities:		
Accounts payable and accrued expenses	\$ 63,007	\$ 53,373
Grant obligations - Les Turner ALS Center at Northwestern Medicine	1,095,000	810,000
Current obligations - operating lease	87,382	85,362
Deferred income	-	13,000
Total current liabilities	<u>1,245,389</u>	<u>961,735</u>
Operating lease, non-current	<u>549,636</u>	<u>637,132</u>
Total liabilities	<u>1,795,025</u>	<u>1,598,867</u>
Net assets:		
Without donor restriction	1,167,421	1,826,066
With donor restriction	324,314	339,201
Total net assets	<u>1,491,735</u>	<u>2,165,267</u>
Total liabilities and net assets	<u>\$ 3,286,760</u>	<u>\$ 3,764,134</u>

See accompanying notes to financial statements.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Statement of Activities and Change in Net Assets

<i>Year Ended December 31,</i>	2023		
	Without Donor Restrictions	With Donor Restrictions	Total
Public support and revenues:			
Special events:	\$ 1,635,830	\$ 5,000	\$ 1,640,830
Direct special events costs	885,074	-	885,074
Net special events support	750,756	5,000	755,756
Grants	42,500	-	42,500
Individuals, corporations, and foundations	919,864	861,923	1,781,787
	1,713,120	866,923	2,580,043
Net assets released from donor restrictions	881,810	(881,810)	-
Total public support and revenues	2,594,930	(14,887)	2,580,043
Interest income	102,365	-	102,365
Total public support, revenue, and interest income	2,697,295	(14,887)	2,682,408
Expenses:			
Direct program services:			
Les Turner ALS Center at Northwestern Medicine:			
Research	720,000	-	720,000
Lois Insolita ALS Clinic	375,000	-	375,000
Endowed Fund	100,000	-	100,000
Education	22,914	-	22,914
Support services	839,039	-	839,039
Education	580,770	-	580,770
Total direct program services	2,637,723	-	2,637,723
Core mission support:			
Development	449,089	-	449,089
Management and general	269,128	-	269,128
Total core mission support	718,217	-	718,217
Change in net assets	(658,645)	(14,887)	(673,532)
Net assets - Beginning of year	1,826,066	339,201	2,165,267
Net assets - End of year	\$ 1,167,421	\$ 324,314	\$ 1,491,735

See accompanying notes to financial statements.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Statement of Activities and Change in Net Assets

<i>Year Ended December 31,</i>	2022		
	Without Donor Restrictions	With Donor Restrictions	Total
Public support and revenues:			
Special events:	\$ 1,582,285	\$ 15,000	\$ 1,597,285
Direct special events costs	881,743	-	881,743
Net special events support	700,542	15,000	715,542
Grants	42,500	-	42,500
Individuals, corporations, and foundations	916,047	846,678	1,762,725
Employee Retention Credit	110,621	-	110,621
	1,769,710	861,678	2,631,388
Net assets released from donor restrictions	890,908	(890,908)	-
Total public support and revenues	2,660,618	(29,230)	2,631,388
Interest income	28,645	-	28,645
Total public support, revenue, and interest income	2,689,263	(29,230)	2,660,033
Expenses:			
Direct program services:			
Les Turner ALS Center at Northwestern Medicine:			
Research	500,000	-	500,000
Lois Insolia ALS Clinic	310,000	-	310,000
Endowed Fund	100,000	-	100,000
Education	6,190	-	6,190
Support services	843,451	-	843,451
Education	401,038	-	401,038
Total direct program services	2,160,679	-	2,160,679
Core mission support:			
Development	394,419	-	394,419
Management and general	231,026	-	231,026
Total core mission support	625,445	-	625,445
Change in net assets	(96,861)	(29,230)	(126,091)
Net assets - Beginning of year	1,922,927	368,431	2,291,358
Net assets - End of year	\$ 1,826,066	\$ 339,201	\$ 2,165,267

See accompanying notes to financial statements.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Statement of Functional Expenses

<i>Year Ended December 31, 2023</i>	Direct Program Services						Core Mission Support			
	Les Turner ALS Center at Northwestern Medicine						Total Direct Program Services	Development	Management and General	Total Core Mission Support
	Research	Lois Insolia ALS Clinic	Endowed Fund	Education	Support Services	Education				
Salaries, other compensation, and employee benefits	\$ -	\$ -	\$ -	\$ -	\$ 658,627	\$ 370,522	\$ 1,029,149	\$ 315,359	\$ 129,628	\$ 444,987
Research	720,000	-	-	-	-	-	720,000	-	-	-
Clinical Services	-	375,000	-	-	-	-	375,000	-	-	-
Endowed Fund	-	-	100,000	-	-	-	100,000	-	-	-
Education	-	-	-	22,914	-	-	22,914	-	-	-
Speech equipment, respite, and other assistance programs	-	-	-	-	127,057	-	127,057	-	-	-
Awards, gifts, and honorariums	-	-	-	-	1,928	2,028	3,956	10,489	2,910	13,399
Database management	-	-	-	-	-	9,895	9,895	1,831	150	1,981
Office and miscellaneous	-	-	-	-	20,227	23,406	43,633	45,826	70,971	116,797
Printing, postage, and artwork	-	-	-	-	1,167	77,243	78,410	27,172	2,095	29,267
Public relations	-	-	-	-	-	11,070	11,070	-	-	-
Lease expense	-	-	-	-	14,588	20,179	34,767	18,342	11,101	29,443
Utilities	-	-	-	-	392	657	1,049	596	363	959
Conference and meetings	-	-	-	-	361	18,288	18,649	1,021	1,973	2,994
Insurance - General	-	-	-	-	5,078	2,248	7,326	1,958	2,753	4,711
Interest expense	-	-	-	-	-	-	-	-	355	355
Depreciation and amortization	-	-	-	-	75	27,130	27,205	-	12,190	12,190
Professional fees	-	-	-	-	-	-	-	-	25,476	25,476
Repairs and maintenance	-	-	-	-	9,539	18,104	27,643	26,495	9,163	35,658
Direct special events costs	-	-	-	-	-	-	-	885,074	-	885,074
<b>Total expenses</b>	<b>720,000</b>	<b>375,000</b>	<b>100,000</b>	<b>22,914</b>	<b>839,039</b>	<b>580,770</b>	<b>2,637,723</b>	<b>1,334,163</b>	<b>269,128</b>	<b>1,603,291</b>
Less - Expenses included with public support and revenues	-	-	-	-	-	-	-	(885,074)	-	(885,074)
<b>Total expenses included in the expenses section of the statements of activities</b>	<b>\$ 720,000</b>	<b>\$ 375,000</b>	<b>\$ 100,000</b>	<b>\$ 22,914</b>	<b>\$ 839,039</b>	<b>\$ 580,770</b>	<b>\$ 2,637,723</b>	<b>\$ 449,089</b>	<b>\$ 269,128</b>	<b>\$ 718,217</b>

See accompanying notes to financial statements.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Statement of Functional Expenses

<i>Year Ended December 31, 2022</i>	Direct Program Services						Core Mission Support			
	Les Turner ALS Center at Northwestern Medicine						Total Direct Program Services	Development	Management and General	Total Core Mission Support
	Research	Lois Insolia ALS Clinic	Endowed Fund	Education	Support Services	Education				
Salaries, other compensation, and employee benefits	\$ -	\$ -	\$ -	\$ -	\$ 666,317	\$ 249,812	\$ 916,129	\$ 261,776	\$ 96,477	\$ 358,253
Research	500,000	-	-	-	-	-	500,000	-	-	-
Clinical Services	-	310,000	-	-	-	-	310,000	-	-	-
Endowed Fund	-	-	100,000	-	-	-	100,000	-	-	-
Education	-	-	-	6,190	-	-	6,190	-	-	-
Speech equipment, respite, and other assistance programs	-	-	-	-	118,293	-	118,293	-	-	-
Awards, gifts, and honorariums	-	-	-	-	2,584	1,071	3,655	12,075	1,015	13,090
Database management	-	-	-	-	4,218	6,363	10,581	11,508	3,021	14,529
Office and miscellaneous	-	-	-	-	13,558	20,938	34,496	26,668	67,106	93,774
Printing, postage, and artwork	-	-	-	-	1,217	59,495	60,712	34,004	2,881	36,885
Public relations	-	-	-	-	-	4,392	4,392	88	-	88
Lease expense	-	-	-	-	17,761	17,582	35,343	18,184	9,945	28,129
Utilities	-	-	-	-	457	555	1,012	574	314	888
Conference and meetings	-	-	-	-	4,131	9,160	13,291	2,438	3,473	5,911
Insurance - General	-	-	-	-	8,435	3,106	11,541	3,289	5,970	9,259
Interest expense	-	-	-	-	-	-	-	-	(379)	(379)
Depreciation and amortization	-	-	-	-	75	18,404	18,479	-	14,393	14,393
Professional fees	-	-	-	-	-	-	-	9,515	19,314	28,829
Repairs and maintenance	-	-	-	-	6,405	10,160	16,565	14,300	7,496	21,796
Direct special events costs	-	-	-	-	-	-	-	881,743	-	881,743
<b>Total expenses</b>	<b>500,000</b>	<b>310,000</b>	<b>100,000</b>	<b>6,190</b>	<b>843,451</b>	<b>401,038</b>	<b>2,160,679</b>	<b>1,276,162</b>	<b>231,026</b>	<b>1,507,188</b>
Less - Expenses included with public support and revenues	-	-	-	-	-	-	-	(881,743)	-	(881,743)
<b>Total expenses included in the expenses section of the statements of activities</b>	<b>\$ 500,000</b>	<b>\$ 310,000</b>	<b>\$ 100,000</b>	<b>\$ 6,190</b>	<b>\$ 843,451</b>	<b>\$ 401,038</b>	<b>\$ 2,160,679</b>	<b>\$ 394,419</b>	<b>\$ 231,026</b>	<b>\$ 625,445</b>

See accompanying notes to financial statements.



# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Statements of Cash Flows

<i>Years Ended December 31,</i>	2023	2022
Cash flows from operating activities:		
Cash received from public support and other miscellaneous sources	\$ 3,393,290	\$ 3,857,095
Interest income received	102,364	28,645
Direct special events costs paid	(895,023)	(885,572)
Direct program service expenses paid	(2,351,858)	(2,304,784)
Support service expenses paid	(681,948)	(592,975)
Net cash provided by (used in) operating activities	<u>(433,175)</u>	<u>102,409</u>
Cash flows from investing activities:		
Purchase of property and equipment	(4,810)	(10,281)
Purchase of intangible assets	(50,260)	(22,712)
Purchase of certificates of deposits	-	(1,725,801)
Sale of certificates of deposits	1,601,636	-
Net cash provided by (used in) investing activities	<u>1,546,566</u>	<u>(1,758,794)</u>
Change in cash and cash equivalents	1,113,391	(1,656,385)
Cash and cash equivalents - Beginning of year	<u>945,581</u>	<u>2,601,966</u>
Cash and cash equivalents - End of year	<u>\$ 2,058,972</u>	<u>\$ 945,581</u>

See accompanying notes to financial statements.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### Note 1: Nature of the Organization

Founded in 1977, the Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd. (the "Foundation") is one of the longest-serving ALS groups in the country. The Foundation's support services team helps people living with ALS receive the best quality of care and access to the most promising therapies, and it offers support groups, ALS resources and webinars, and live events to provide answers and encouragement.

Since 1979, the Les Turner ALS Foundation has supported ALS research at Northwestern University. This was followed by the 1986 establishment of the Lois Insolia ALS Clinic ("Clinic"), the first and largest multidisciplinary ALS clinic in the Chicago area. Among the transformative advances made possible through the Foundation's support of ALS research was the 1993 co-discovery of SOD1, the first genetic mutation linked to cause ALS. This research has laid essential groundwork for targeted therapies in ALS, such as in 2023, when Qalsody became the first FDA-approved treatment for a genetic form of the disease, SOD1-ALS.

Today, the Les Turner ALS Center at Northwestern Medicine ("Center") is led by the most well-respected scientists and clinicians in the field, advancing vital research into causes, treatments, and cures for ALS. Through the Clinic, patients have access to enrollment in multi-center clinical trials and dedicated clinical trial coordinators. The Center consists of all ALS research activities at Northwestern Medicine, Northwestern University and the Clinic (see Notes 4 and 10).

The Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd. is a not-for-profit foundation exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. It has been classified as an organization that is not a private foundation under Section 509(a)(2) of the Internal Revenue Code and qualifies for charitable contributions deduction for individual donors up to 60% of adjusted gross income.

The Board of Directors and CEO of the Foundation acknowledge that, to the best of their knowledge, all assets received have been used for the purpose for which they were contributed, or have been accumulated to allow management to conduct the operations of the Foundation as effectively as possible.

### Note 2: Summary of Significant Accounting Policies

#### Method 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.

#### Basis of Presentation

Financial statement presentation follows accounting principles generally accepted in the United States of America for financial presentation of not-for-profit organizations. Such principles provide that the Foundation is required to report information regarding its financial position and activities according to two classes of net assets. A definition and description of each class follows:

**Net Assets Without Donor Restriction** - Net assets available for use in general operations and not subject to donor (or certain grantor) restrictions.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### **Note 2: Summary of Significant Accounting Policies** (Continued)

#### **Basis of Presentation** (Continued)

**Net Assets With Donor Restriction** - Net assets subject to donor-imposed or certain grantor-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 explicit 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.

As of December 31, 2023 and 2022, the Foundation had \$324,314 and \$339,201, respectively, with donor restriction.

#### **Cash and Cash Equivalents**

Cash equivalents consist of highly liquid investments with an initial maturity of three months or less. Fair value approximates carrying amounts. The Foundation utilizes an Insured Cash Sweep service to earn interest, maintain liquidity and to have Federal Deposit Insurance Corporation coverage on its funds at substantially all times.

#### **Certificates of Deposit**

Certificates of deposit are carried at cost plus accrued interest. The Foundation participates in a program called certificate of deposit account registry service (CDARS) to have Federal Deposit Insurance Corporation (FDIC) coverage on its funds at substantially all times.

#### **Revenue Recognition**

Public support received is recorded as net assets without donor restriction or net assets with donor restriction, depending on the existence and/or nature of any donor restrictions. All net assets with donor restriction support is reported as an increase in net assets with donor restrictions, depending on the nature of the restriction. When a donor restriction expires (that is, when a stipulated time restriction ends or the purpose of restriction is accomplished), net assets with donor restriction are reclassified to net assets without donor restriction and reported in the statement of activities as net assets released from restrictions.

The Foundation records special events revenue equal to the fair value of direct benefits to donors, and contribution income for the excess received when the event takes place. The Foundation receives consideration at the time the attendee registers to attend, which is generally in advance of the events. The direct benefit to donors associated with the events is reported as a liability (deferred income) and recognized as revenue when the event occurs. Deferred income related to special events totaled \$0 and \$13,000 as of December 31, 2023 and 2022, respectively.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### **Note 2: Summary of Significant Accounting Policies** (Continued)

#### **Contributions Receivable**

The Foundation's management periodically analyzes the promises to give and contributions receivable and considers whether an allowance for possible losses on the collection of these promises is appropriate. The evaluations take into consideration such factors as prior loss experience, current economic conditions, and collectability. Management has determined that all promises to give and contributions receivable are collectible as of December 31, 2023 and 2022, and has not provided for an allowance for possible losses.

#### **Donated Equipment and Services**

Donated equipment and services have not been reflected in the accompanying financial statements since no objective basis is available to measure the value of such inventory and services. The Foundation does receive and lend equipment as part of its support services.

The Foundation receives a substantial amount of services donated by volunteers. 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 Foundation. No amounts have been recognized in the financial statements for these services because they do not meet the criteria for recognition as contributed services.

#### **Property and Equipment**

The Foundation capitalizes the cost of property and equipment purchases over \$500. Depreciation and amortization is provided over the estimated useful lives of the related assets or the life of the lease using the straight-line method. Depreciation and amortization expense was \$39,395 and \$32,872 for the years ended December 31, 2023 and 2022, respectively.

#### **Intangible Assets**

Intangible assets are comprised of software licenses, online educational resources, and website development costs, which have a cost of \$201,267 and \$151,007 as of December 31, 2023 and 2022, respectively, and are amortized on a straight-line basis over their estimated three to five year lives. Accumulated amortization as of December 31, 2023 and 2022, was \$90,817 and \$61,625, respectively, and amortization expense for the years then ended was \$29,192 and \$23,737, respectively.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### Note 2: Summary of Significant Accounting Policies (Continued)

#### Intangible Assets (Continued)

Estimated amortization expense on intangibles for each of the next five years is as follows:

<i>Year Ending December 31,</i>	
2024	\$ 32,304
2025	31,968
2026	28,444
2027	12,881
2028	4,853
Total	\$ 110,450

#### Functional Allocation of Expenses

The costs of providing direct program and core mission support services have been summarized on a functional basis in the statements of activities and changes in net assets. The statement of functional expenses present the natural classification detail of expenses by function. Accordingly, certain costs have been allocated among the direct programs and core mission support services benefited. Expenses by function have been allocated among direct program services and core mission support classifications on the basis of time records and on the square footage of the office space.

#### Income Taxes

The Foundation is a tax-exempt corporation as permitted by section 501(c)(3) of the Internal Revenue Code. The Foundation believes it has appropriate support for any tax positions taken and, as such, does not have any uncertain tax positions that are material to the financial statements.

#### Use of Estimates

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

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### **Note 2: Summary of Significant Accounting Policies** (Continued)

#### **ASC 842 Lease Accounting**

The Foundation is a lessee in operating leases. If the contract provides the Foundation the right to substantially all the economic benefits and the right to direct the use of the identified asset, it is considered to be or contain a lease. Right-of-use ("ROU") assets and lease liabilities are recognized at the lease commencement date based on the present value of the future lease payments over the expected lease term. The ROU asset is also adjusted for any lease prepayments made, lease incentives received, and initial direct costs incurred.

The lease liability is initially and subsequently recognized based on the present value of its future lease payments. Variable payments are included in the future lease payments when those variable payments depend on an index or a rate. Increases (decreases) to variable lease payments due to subsequent changes in an index or rate are recorded as variable lease expense (income) in the future period in which they are incurred.

The discount rate used is the implicit rate in the lease contract, if it is readily determinable, or the risk-free rate for a term similar to the underlying lease as the discount rate.

The ROU asset for operating leases is subsequently measured throughout the lease term at the amount of the remeasured lease liability (i.e., present value of the remaining lease payments), plus unamortized initial direct costs, plus (minus) any prepaid (accrued) lease payments, less the unamortized balance of lease incentives received, and any impairment recognized. For operating leases with lease payments that fluctuate over the lease term, the total lease costs are recognized on a straight-line basis over the lease term.

For all underlying classes of assets, the Foundation has elected to not recognize ROU assets and lease liabilities for short-term leases that have a lease term of 12 months or less at lease commencement and do not include an option to purchase the underlying asset that the Foundation is reasonably certain to exercise. Leases containing termination clauses in which either party may terminate the lease without cause and the notice period is less than 12 months are deemed short-term leases with lease costs included in short-term lease expense. The Foundation recognizes short-term lease cost on a straight-line basis over the lease term.

The Foundation made an accounting policy election for right of use assets - operating to not separate the lease components of a contract and its associated non-lease components.

#### **New Accounting Pronouncement**

Accounting Standards Update (ASU) No. 2016-13, Measurement of Credit Losses on Financial Instruments, requires the Foundation to present financial assets measured at amortized cost (including accounts receivable) at the net amount expected to be collected over their remaining contractual lives. Estimated credit losses are based on relevant information about historical experience, current conditions, and reasonable and supportable forecasts that affect the collectability of the reported amounts.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

### Note 2: Summary of Significant Accounting Policies (Continued)

#### New Accounting Pronouncement (Continued)

The Foundation adopted ASU No. 2016-13 on January 1, 2023. The net impact to net assets would have been immaterial, thus no adjustment was made to net assets. Results for the year ended December 31, 2023, are presented under Accounting Standards Codification (ASC) 326 while prior period amounts continue to be reported in accordance with previously applicable accounting standards generally accepted in the United States (US GAAP). There was no impact to the the Foundation upon adoption of the ASU.

#### Subsequent Events

Based on management's evaluation, there were no subsequent event disclosures through July 1, 2024, which is the date these financial statements were available to be issued.

### Note 3: Liquidity and Availability of Financial Resources

The Foundation maintains and adheres to a cash and investment policy. The policy is built upon the idea of reducing fiscal risk by preserving principal while enhancing the cash returns above market net returns, when possible. The Foundation maintains the following conservative fiscal practices in order to adhere to its policy. The Foundation assigns certain responsibilities to its Audit and Finance Committee to oversee the policy. The various cash accounts may be diversified among multiple financial institutions to avoid exceeding the FDIC limits. As part of its liquidity management, the Foundation may invest cash in excess of anticipated liquidity needs into various short-term investments including certificates of deposits, short term Treasury instruments and Insured Cash Sweep services. The Foundation has a goal to maintain cash on hand in its main checking account to meet 30 days of normal operating expenses, which are, on average, approximately \$170,000.

The following table reflects the Foundation's financial assets available for general operating expenditures.

<i>As of December 31,</i>	2023	2022
Cash and cash equivalents	\$ 2,058,972	\$ 945,581
Certificates of deposit	124,165	1,725,801
Contributions receivable	162,726	103,899
Other receivable	97,333	97,333
Total financial assets	2,443,196	2,872,614
Less: Grant obligations - Les Turner ALS Center at Northwestern Medicine	1,095,000	810,000
Less: Net assets with donor restrictions	324,314	339,201
Total available for general operating expenditures	\$ 1,023,882	\$ 1,723,413

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

### Note 4: Grant Obligations

Unconditional gift obligations consist of research and other gifts which have been awarded to fund the Les Turner ALS Center at Northwestern Medicine as further described in Note 10; certain grant obligation amounts had not yet been paid as of the date of the statements of financial position. They are summarized as follows:

<i>As of December 31,</i>	2023	2022
Research	\$ 685,000	\$ 400,000
Lois Insolia ALS Clinic	310,000	310,000
Endowed Fund	100,000	100,000
<b>Total grants payable to Les Turner ALS Center at Northwestern Medicine</b>	<b>\$ 1,095,000</b>	<b>\$ 810,000</b>

### Note 5: Net Assets with Donor Restrictions

Net assets with donor restrictions are restricted for the following purposes:

<i>As of December 31,</i>	2023	2022
Support Services and Education	\$ 25,766	\$ 39,158
Smith Education Fund	7,500	51,611
Nelson Respite Fund	9,150	-
Boughton Equipment Fund	-	45,879
Transportation - Rosen	-	2,748
ALS Decision Tool Fund	166,898	84,805
Joseph B. Heller Endowment Fund - Perpetual in nature	115,000	115,000
<b>Total</b>	<b>\$ 324,314</b>	<b>\$ 339,201</b>

### Note 6: Endowment Funds

The Foundation's endowment consists of one fund with donor restrictions, the Joseph B. Heller Endowment Fund, created in 2022. The endowment's primary objective is to maintain and grow its principal in perpetuity. As required by GAAP, net assets associated with endowment funds, including funds designated by the Board of Directors, are classified and reported based on the existence or absence of donor-imposed restrictions.



# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

### Note 6: Endowment Funds (Continued)

The Board of Directors has interpreted the Illinois Uniform Prudent Management of Institutional Funds Act (UPMIFA) as requiring the preservation of the fair value of the original gift as of the date of the donor-restricted endowment funds, unless there are explicit donor stipulations to the contrary. At December 31, 2023, there were no such donor stipulations. As a result of this interpretation, the Foundation retains in perpetuity (a) the original value of initial and subsequent gift amounts (including promises to give net of discount and allowance for doubtful accounts, including promises to give at fair value) donated to the endowment and (b) any accumulations to the endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added. Donor-restricted amounts not retained in perpetuity are subject to appropriation for expenditure by the Foundation in a manner consistent with the standard of prudence prescribed by UPMIFA. The Foundation considers the following factors in making a determination to appropriate or accumulate donor-restricted endowment funds:

- The duration and preservation of the fund
- The purposes of the organization and the donor-restricted endowment fund
- General economic conditions
- The possible effect of inflation and deflation
- The expected total return from income and the appreciation of investments
- Other resources of the organization
- The investment policies of the organization

The primary long-term financial objective for the Foundation's endowment funds is to preserve the real purchasing power of endowment assets and income. The endowment funds are managed to optimize the long run total rate of return on invested assets, assuming a prudent level of risk. The endowed funds are invested in accordance with the Foundation's cash and investment policy, which requires all funds to be invested in certificates of deposits and Insured Cash Sweep services, which have FDIC coverage on the funds at substantially all times, and short-term Treasury instruments. In accordance with donor intention, the net income only from the endowment may be used annually as directed by the Board of Directors of the Foundation.

Composition of endowment net assets for the years ended December 31, 2023 and 2022, were as follows:

	2023			2022		
	Without Donor Restriction	With Donor Restriction	Total	Without Donor Restriction	With Donor Restriction	Total
Donor - restricted endowment fund	\$ -	\$ 115,000	\$ 115,000	\$ -	\$ 115,000	\$ 115,000
Total	\$ -	\$ 115,000	\$ 115,000	\$ -	\$ 115,000	\$ 115,000

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

### Note 6: Endowment Funds (Continued)

Changes in endowment net assets for the years ended December 31, 2023 and 2022, were as follows:

	Without Donor Restriction	With Donor Restriction	Total
Endowment net assets at January 1, 2022	\$ -	\$ -	\$ -
Contributions to endowment funds during 2022	-	115,000	115,000
Endowment net assets at December 31, 2022	-	115,000	115,000
Endowment net assets at December 31, 2023	\$ -	\$ 115,000	\$ 115,000

### Note 7: Employee Retention Tax Credit

The Foundation filed for an employee retention tax credit related to quarterly periods from 2020 and 2021. The Foundation views these credits as a grant by analogizing to guidance in IAS 20, *Accounting for Government Grants and Disclosure of Government Assistance*. For the year ended December 31, 2022, the Foundation recorded grant revenue of \$110,621 on the statements of activities and changes in net assets with a corresponding other receivable on the statements of financial position.

### Note 8: Leases

The Foundation leases office and storage space. The leases entered into include one or more options to renew. The renewal terms can extend the lease term for five years. The exercise of lease renewal options is at the Foundation's sole discretion. Renewal option periods are included in the measurement of the ROU asset and lease liability when the exercise is reasonably certain to occur.

The depreciable life of assets and leasehold improvements are limited by the expected lease term, unless there is a transfer of title or purchase option reasonably certain of exercise.

The Foundation's lease agreements do not contain any material residual value guarantees or material restrictive covenants. Payments due under the lease contracts include fixed payments plus, for some of the Foundation's leases, variable payments. The Foundation's office space lease requires it to make variable payments for the Foundation's proportionate share of the building's property taxes, insurance, and common area maintenance. These variable lease payments are not included in lease payments used to determine the lease liability and are recognized as variable costs when incurred.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

### Note 8: Leases (Continued)

Components of lease expense consisted of the following at December 31, 2023 and 2022:

	2023	2022
Lease cost		
Operating lease cost	\$ 97,142	\$ 97,142
Variable lease cost	11,101	5,411
<b>Total lease cost</b>	<b>\$ 108,243</b>	<b>\$ 102,553</b>

Total lease costs of \$44,033 and \$39,081 are included in direct special event costs on the statement of functional expenses for the years ended December 31, 2023 and 2022, respectively.

Supplemental cash flow information related to leases is as follows at December 31, 2023 and 2022:

	2023	2022
Operating cash flows from operating leases	\$ 96,277	\$ 66,129

The following summarizes the weighted-average remaining lease term and weighted-average discount rate as of December 31, 2023 and 2022:

<i>Years Ended December 31,</i>	2023	2022
Weighted-average remaining lease term - Operating leases	6.6	7.6
Weighted-average discount rate - Operating leases	1.6 %	1.6 %

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### Note 8: Leases (Continued)

Maturities of lease liabilities are as follows:

<i>Years Ending December 31,</i>	
2024	\$ 96,809
2025	98,661
2026	100,513
2027	102,365
2028	104,217
Thereafter	168,830
Total lease payments	671,395
Less imputed interest	(34,377)
Total	\$ 637,018

### Note 9: Retirement Plan

The Foundation maintains the Les Turner ALS Foundation 401(k) Plan for all employees meeting certain eligibility requirements. For the years ended December 31, 2023 and 2022, employer contributions were \$32,452 and \$25,984, respectively.

### Note 10: Les Turner ALS Center at Northwestern Medicine (Center)

In September 2014, the Foundation entered into a nonbinding gift agreement with Northwestern University Feinberg School of Medicine ("Northwestern") to establish the Center. The purpose of the agreement is to provide financial resources to Northwestern to benefit, under one umbrella, research, clinical activities, and education in the area of amyotrophic lateral sclerosis. The Foundation's nonbinding pledge to Northwestern is to give no less than a total of \$10 million in annual gifts totaling \$1 million or more over a period of 10 years commencing on January 1, 2015, and concluding on December 31, 2024.

The overall \$10 million commitment from the Foundation is allocated as follows over 10 years:

- \$9 million to expendable funds (minimum of \$900,000 annually) and
- \$1 million (minimum of \$100,000 annually) to the Les Turner ALS Center at Northwestern Medicine Endowed Fund (Endowed Fund), from which the expendable income is used to support the Center's ongoing activities.

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

### Note 10: Les Turner ALS Center at Northwestern Medicine (Center) (Continued)

The \$9 million pledge in expendable funding provided by the Foundation allowed the establishment of the Center and will provide annual support for the Center's operations for the ten year period. In addition, a total of \$250,000 is required to permanently endow the Endowed Fund and a total of \$10 million is required to endow the Center in perpetuity. This includes the \$1 million from the Foundation mentioned above. The additional \$9 million in endowed funds are being raised from the joint efforts of the Foundation and Northwestern. The gift agreement does not hold the Foundation responsible for the additional \$9 million in endowed funds. Per the gift agreement, if the full \$10 million to endow the Center is not achieved by 2024, the Foundation can enter into another agreement with Northwestern providing for sufficient sustained support for the Center. Under the terms of the nonbinding gift agreement, since the Endowed Fund has received funds in excess of \$250,000, it is permanently endowed.

As the gift agreement is nonbinding, no long-term liability has been accrued. During 2023 and 2022, the Board appropriated \$1,095,000 (of which \$0 was funded in 2023) and \$810,000 (of which \$0 was funded in 2022) for the Foundation's 2023 and 2022 gift to Northwestern. In addition, other gifts may be made throughout the year. The unpaid portions of these appropriations are included in the grant obligations summarized in Note 4. Each year's appropriation included \$100,000 which was credited toward the Endowed Fund as described above.

During 2023 and 2022, the Center and the Endowed Fund received contributions, on a cash basis, from Board appropriations and other public support in the following amounts:

	December 31, 2023		
	Endowed Fund	Expendable Funds	Total
Board appropriated	\$ 100,000	\$ 810,000	\$ 910,000
Other public support	10,600	5,656	16,256
<b>Total contributions</b>	<b>\$ 110,600</b>	<b>\$ 815,656</b>	<b>\$ 926,256</b>

	December 31, 2022		
	Endowed Fund	Expendable Funds	Total
Board appropriated	\$ 100,000	\$ 980,000	\$ 1,080,000
Other public support	13,250	455	13,705
<b>Total contributions</b>	<b>\$ 113,250</b>	<b>\$ 980,455</b>	<b>\$ 1,093,705</b>

# Les Turner Amyotrophic Lateral Sclerosis Foundation, Ltd.

## Notes to Financial Statements

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### **Note 10: Les Turner ALS Center at Northwestern Medicine (Center)** (Continued)

Contributions to the Center and the Endowed Fund that were received directly via other public support are not included in the statement of activities and change in net assets for the Foundation. As of December 31, 2023, the Foundation had paid an additional \$298,667 above the nonbinding pledge, on a cash basis, and the contributions to the Endowed Fund were \$5,001,629. As of December 31, 2022, the remaining amount of the nonbinding pledge, on a cash basis was \$711,333 and the contribution to to the Endowment Fund was \$4,891,029.

### **Note 11: Subsequent Event**

Since the nonbinding gift agreement with Northwestern concludes on December 31, 2024, the Foundation is currently negotiating a new gift agreement with Northwestern providing for sufficient sustained support for the Les Turner ALS Center.