

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**FINANCIAL STATEMENTS**  
**DECEMBER 31, 2023 AND 2022**  
**AND**  
**INDEPENDENT ACCOUNTANTS' REVIEW REPORT**

## TABLE OF CONTENTS

Independent Accountants' Review Report.....	1
Financial Statements:	
Statements of Financial Position .....	2
Statements of Activities and Changes in Net Assets.....	3
Statements of Functional Expenses .....	5
Statements of Cash Flows.....	6
Notes to Financial Statements .....	7

## Independent Accountants' Review Report

To the Board of Directors  
Koolen-de Vries Syndrome Foundation

We have reviewed the accompanying financial statements of Koolen-de Vries Syndrome Foundation (a not-for-profit organization), which comprise the statements of financial position as of December 31, 2023 and 2022, and the related statements of activities and changes in net assets, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements. A review includes primarily applying analytical procedures to management's financial data and making inquiries of organization's management. A review is substantially less in scope than an audit, the objective of which is the expression of an opinion regarding the financial statements as a whole. Accordingly, we do not express such an opinion.

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

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement whether due to fraud or error.

### *Accountants' Responsibility*

Our responsibility is to conduct the review engagements in accordance with Statements on Standards for Accounting and Review Services promulgated by the Accounting and Review Services Committee of the AICPA. Those standards require us to perform procedures to obtain limited assurance as a basis for reporting whether we are aware of any material modifications that should be made to the financial statements for them to be in accordance with accounting principles generally accepted in the United States of America. We believe that the results of our procedures provide a reasonable basis for our conclusion.

We are required to be independent of Koolen-de Vries Syndrome Foundation and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements related to our reviews.

### *Accountants' Conclusion*

Based on our reviews, we are not aware of any material modifications that should be made to the accompanying financial statements in order for them to be in accordance with accounting principles generally accepted in the United States of America.

*McCauley, Rose & Mills, L.L.P.*

Frisco, Texas  
August 14, 2024

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**STATEMENTS OF FINANCIAL POSITION**  
**DECEMBER 31, 2023 AND 2022**

	2023	2022
<b>Assets</b>		
Cash and cash equivalents, unrestricted	\$ 374,997	\$ 304,522
Cash and cash equivalents, restricted	205,619	294,831
Pledges receivable, unrestricted	-	206
Total assets	\$ 580,616	\$ 599,559
<b>Liabilities and Net Assets</b>		
Liabilities	\$ -	\$ -
Net assets:		
Without donor restrictions	374,997	304,728
With donor restrictions	205,619	294,831
Total net assets	580,616	599,559
Total liabilities and net assets	\$ 580,616	\$ 599,559

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS**  
**YEAR ENDED DECEMBER 31, 2023**

	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Revenues and other support:			
Donations and grants	\$ 115,057	\$ 144,963	\$ 260,020
Interest income	7	-	7
Other program revenue	-	45,594	45,594
	<u>115,064</u>	<u>190,557</u>	<u>305,621</u>
Net assets released from restrictions:			
Satisfaction of purpose restrictions	<u>279,769</u>	<u>(279,769)</u>	<u>-</u>
Total revenues and other support	<u>394,833</u>	<u>(89,212)</u>	<u>305,621</u>
Expenses:			
Research	170,856	-	170,856
Summit event	107,158	-	107,158
Supplies	188	-	188
Travel	2,881	-	2,881
Professional fees	8,526	-	8,526
Telephone	72	-	72
Dues and subscriptions	4,440	-	4,440
Postage and shipping	956	-	956
Advertising	14,293	-	14,293
Bank charges and fees	2,542	-	2,542
Insurance	1,073	-	1,073
Licenses and fees	6,821	-	6,821
Website	4,552	-	4,552
Bad debt expense	206	-	206
Total expenses	<u>324,564</u>	<u>-</u>	<u>324,564</u>
Change in net assets	70,269	(89,212)	(18,943)
Net assets at beginning of year	<u>304,728</u>	<u>294,831</u>	<u>599,559</u>
Net assets at end of year	<u>\$ 374,997</u>	<u>\$ 205,619</u>	<u>\$ 580,616</u>

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS**  
**YEAR ENDED DECEMBER 31, 2022**

	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Revenues and other support:			
Donations and grants	\$ 70,065	\$ 167,393	\$ 237,458
Interest income	7	-	7
Other program revenue	-	-	-
	<u>70,072</u>	<u>167,393</u>	<u>237,465</u>
Net assets released from restrictions:			
Satisfaction of purpose restrictions	<u>10,842</u>	<u>(10,842)</u>	<u>-</u>
Total revenues and other support	<u>80,914</u>	<u>156,551</u>	<u>237,465</u>
Expenses:			
Research	10,842	-	10,842
Summit event	150	-	150
Travel	2,689	-	2,689
Professional fees	8,776	-	8,776
Telephone	60	-	60
Dues and subscriptions	4,494	-	4,494
Postage and shipping	407	-	407
Advertising	7,387	-	7,387
Bank charges and fees	675	-	675
Insurance	1,457	-	1,457
Licenses and fees	2,150	-	2,150
Website	<u>2,476</u>	<u>-</u>	<u>2,476</u>
Total expenses	<u>41,563</u>	<u>-</u>	<u>41,563</u>
Change in net assets	39,351	156,551	195,902
Net assets at beginning of year	<u>265,377</u>	<u>138,280</u>	<u>403,657</u>
Net assets at end of year	<u>\$ 304,728</u>	<u>\$ 294,831</u>	<u>\$ 599,559</u>

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION  
STATEMENTS OF FUNCTIONAL EXPENSES  
YEARS ENDED DECEMBER 31, 2023 AND 2022**

	2023				2022			
	Program Services	Management and General	Fundraising	Total	Program Services	Management and General	Fundraising	Total
Research	\$ 170,856	\$ -	\$ -	\$ 170,856	\$ 10,842	\$ -	\$ -	\$ 10,842
Summit event	107,158	-	-	107,158	150	-	-	150
Supplies	94	94	-	188	-	-	-	-
Travel	2,881	-	-	2,881	2,689	-	-	2,689
Professional fees	-	8,526	-	8,526	-	8,776	-	8,776
Telephone	54	18	-	72	45	15	-	60
Dues and subscriptions	3,330	1,110	-	4,440	3,371	1,124	-	4,494
Postage and shipping	717	239	-	956	305	102	-	407
Advertising	7,147	-	7,146	14,293	3,694	-	3,693	7,387
Bank charges and fees	1,906	636	-	2,542	506	169	-	675
Insurance	-	1,073	-	1,073	-	1,457	-	1,457
Licenses and fees	-	6,821	-	6,821	-	2,150	-	2,150
Website	2,276	1,138	1,138	4,552	1,238	619	619	2,476
Bad debt expense	-	206	-	206	-	-	-	-
	<u>\$ 296,419</u>	<u>\$ 19,861</u>	<u>\$ 8,284</u>	<u>\$ 324,564</u>	<u>\$ 22,840</u>	<u>\$ 14,411</u>	<u>\$ 4,312</u>	<u>\$ 41,563</u>

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION  
STATEMENTS OF CASH FLOWS  
YEARS ENDED DECEMBER 31, 2023 AND 2022**

	<b>2023</b>	<b>2022</b>
<b>Operating Activities:</b>		
(Decrease) increase in net assets	\$ (18,943)	\$ 195,902
Adjustment to reconcile change in net assets to net cash used in operating activities:		
Change in operating assets and liabilities:		
Pledges receivable, unrestricted	206	62,937
Net cash used in operating activities	(18,737)	258,839
Net (decrease) increase in cash and cash equivalents	(18,737)	258,839
Cash and cash equivalents at beginning of year	599,353	340,514
Cash and cash equivalents at end of year	\$ 580,616	\$ 599,353
<b>Reconciliation of cash and cash equivalents, end of year:</b>		
Cash and cash equivalents, unrestricted	\$ 374,997	\$ 304,522
Cash and cash equivalents, restricted	205,619	294,831
<b>Cash and cash equivalents, end of year</b>	<b>\$ 580,616</b>	<b>\$ 599,353</b>

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS (CONTINUED)**  
**DECEMBER 31, 2023 AND 2022**

**Note 1 – Description of Organization**

Koolen-de Vries Syndrome Foundation (the “Foundation”) is a nonprofit organization incorporated under the laws of the Missouri Nonprofit Corporation Act in 2013. The mission of the Foundation is to educate, increase awareness and promote research for the support and enrichment of individuals living with Koolen-de Vries Syndrome and their families. The programs, events and activities performed to carry out the Foundation’s mission are governed by its Board of Directors, in collaboration with its Medical Advisory Board and the assistance of countless volunteers. Each year, the Foundation also receives support from hundreds of donors, which is critical to supporting the ongoing mission of education, awareness and research.

**Note 2 – Summary of Significant Accounting Policies**

*Basis of Accounting*

The accompanying financial statements have been prepared on the accrual basis of accounting in accordance with U.S. generally accepted accounting principles ("GAAP"). Under this method of accounting, revenue is recognized when amounts are earned and when the amount and timing of the revenue can be reasonably estimated. Expenses are recognized when they are incurred. Net assets, revenues, and expenses are classified based on the existence or absence of donor-imposed restrictions. Accordingly, net assets and changes therein are classified and reported as follows:

*Net assets without donor restrictions:* Net assets that are not subject to donor-imposed restrictions and may be expended for any purpose in performing the primary objectives of the foundation. These net assets may be used at the discretion of the Foundation's management and the board of directors.

*Net assets with donor restrictions:* Net assets subject to donor-imposed restrictions that will be met by the occurrence of a specific event or passage of time. Other donor-imposed restrictions are perpetual in nature, whereby the donor has stipulated the funds be maintained in perpetuity. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statement of activities as net assets released from restrictions.

*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 and disclosure of contingent assets and liabilities at the date of the financial statements, and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

*Functional Expenses*

The costs of providing program and other activities are summarized on a functional basis in the statement of activities and changes in net assets. Accordingly, certain costs have been allocated among program services and supporting services benefited. Such allocations are determined by management on an equitable basis.

*Cash and Cash Equivalents*

The Foundation's cash consists of cash on deposit with banks. Cash equivalents represent cash, money market funds or short-term investments with original maturities of three months or less from the date of purchase.

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS (CONTINUED)**  
**DECEMBER 31, 2023 AND 2022**

**Note 2 – Summary of Significant Accounting Policies (Continued)**

*Restricted Cash*

As of December 31, 2023, the Foundation has cash totaling \$205,619, restricted for research on Koolen-de Vries syndrome. The purpose of these funds is to support ongoing research efforts aimed at understanding the genetic causes, improving diagnostic methods, and developing new treatments for this rare genetic disorder.

*Pledges Receivable*

Unconditional promises to give that are expected to be collected within one year are recorded at net realizable value. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of their estimated future cash flows. The discounts on those amounts are computed using risk-adjusted interest rates applicable to the years in which the promises are received. Discount amortization is included in contribution revenue.

ASU No. 2016-13, Financial Instruments - Credit Losses (Topic 326): Measurement of Credit Losses on Financial Instruments requires usage of the current expected credit loss methodology to make judgments as to the Foundation's ability to collect outstanding receivables and provide allowances for a portion of receivables over the lifetime of the receivables. The allowance for accounts receivable represents management's estimate of probable non-payments and credit losses, as determined based on a review of past-due balances and other specific account data. See "Recently Adopted Accounting Pronouncements" below for more information.

Based upon historical collection experience, management has determined that no provision for credit losses is necessary. During the year ended 2023, the Foundation wrote off \$206 of pledges receivable.

*Donations and Grants Support*

Donations and grants received are recorded as net assets without donor restrictions or net assets with donor restrictions, depending on the existence and/or nature of any donor-imposed restrictions. Donations and grants that are restricted by the donor are reported as an increase in net assets without donor restrictions if the restriction expires in the reporting period in which the donation or grant is recognized. All other donor-restricted donations and grants are reported as an increase in net assets with donor restrictions, depending on the nature of restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions.

Donated or granted property and equipment are recorded at fair value at the date of donation. Donations and grants with donor-imposed stipulations regarding how long the assets must be used are recorded as net assets with donor restrictions; otherwise, the donations and grants are recorded as net assets without donor restrictions. There were no donated or granted property and equipment as of or for the years ended December 31, 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 substantially met. Conditional gifts received prior to the satisfaction of conditions are recorded as refundable advances.

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS (CONTINUED)**  
**DECEMBER 31, 2023 AND 2022**

**Note 2 – Summary of Significant Accounting Policies (Continued)**

Expenses are reported as decreases in net assets without donor restrictions. Gains and losses on investments and other assets or liabilities are reported as increases or decreases in net assets without donor restrictions unless their use is restricted by explicit donor stipulation or by law.

*Grants*

Grants are recognized as an expense when the unconditional promise to give is approved. Conditional promises to give are recognized as grant expense in the period in which the recipient meets the terms of the condition.

*Concentrations of Credit Risk*

Financial instruments that potentially subject the Foundation to concentrations of credit risk consist principally of cash and cash equivalents and pledges receivable. The Foundation maintains its cash and cash equivalents primarily in one financial institution, which may at times exceed amounts covered by the U.S. Federal Deposit Insurance Company (“FDIC”). The Foundation's cash and cash equivalent accounts have been placed with high credit quality financial institutions. The Foundation has not experienced, nor does it anticipate, any losses with respect to such accounts.

*Advertising Costs*

The costs of advertising are expensed as incurred and totaled \$14,293 and \$7,387 for the years ended December 31, 2023 and 2022, respectively.

*Income Taxes*

The Foundation is a not-for-profit organization and is exempt from income taxes under Section 501(c)(3) of the Internal Revenue Code, except for taxes on unrelated business income. There was no Federal income tax expense for the years ended December 31, 2023 and 2022. The Foundation believes there are no uncertain income tax positions at December 31, 2023 and 2022. Its tax returns for the last four years remain subject to examination.

*Recently Adopted Accounting Pronouncements*

On January 1, 2023, the Foundation adopted Financial Accounting Standards Board (FASB) Accounting Standards Update (ASU) 2016-13, Financial Instruments - Credit Losses (Topic 326): Measurement of Credit Losses on Financial Instruments, as amended (ASU 2016-13), which modifies the measurement of expected credit losses on certain financial instruments. The Foundation adopted this new guidance utilizing the modified retrospective transition method and accordingly, the new guidance was applied to financial assets measured at amortized cost (primarily trade receivables and contract assets) that existed as of January 1, 2023 (the date of initial application). The adoption of ASU 2016-13 did not have a material impact on the Foundation's financial statements but did change how the allowance for credit losses is determined.

*See accompanying notes to financial statements*

**KOOLEN-DE VRIES SYNDROME FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS (CONTINUED)**  
**DECEMBER 31, 2023 AND 2022**

**Note 3 – Availability and Liquidity**

The following represents the Foundation’s financial assets at December 31, 2023 and 2022:

	<b>2023</b>	<b>2022</b>
Financial assets at year end:		
Cash and cash equivalents, unrestricted	\$ 374,997	\$ 304,522
Pledges receivable, unrestricted	-	206
	\$ 374,997	\$ 304,728

The Foundation’s goal is generally to maintain financial assets to meet 90 days of general expenditures. As part of its liquidity plan, excess cash is invested in a bank deposit savings account.

**Note 4 – Net Assets with Donor Restrictions**

Net assets with donor restrictions are donations and grants restricted for (1) expenses incurred to support and promote research of Koolen-de Vries Syndrome and (2) expenses related to the biennial Patient Advocacy Summit event. For the years ended December 31, 2023 and 2022, net assets of \$279,769 and \$10,842, respectively, were released from donor restrictions for research and summit expenditures.

**Note 5 – Patient Advocacy Summit**

The Foundation hosts a bi-annual summit to offer education, networking, and advocacy training for those affected by Koolen-de Vries syndrome. No summit was held in 2022. For the year ended December 31, 2023, summit-related expenses included the following:

Summit expenses:	
Meals and catering	\$ 48,276
Supplies	6,467
Equipment rental	10,252
Professional services	17,984
Stipends and travel-related expenses	24,179
	\$ 107,158

**Note 6 – Subsequent Events**

The Foundation evaluated subsequent events through August 14, 2024, the date these financial statements were issued. Management has determined that there were no other subsequent events that require recognition or disclosure in the financial statements.

*See accompanying notes to financial statements*