Financial Statements as of and for the Years Ended December 31, 2022 and 2021 and Independent Auditors' Report

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### INDEPENDENT AUDITORS' REPORT

To the Board of Directors of The RYR-1 Foundation

### **Opinion**

We have audited the accompanying financial statements of The RYR-1 Foundation (a nonprofit organization), which comprise the statements of financial position as of December 31, 2022 and 2021, 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.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The RYR-1 Foundation as of December 31, 2022 and 2021, 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.

### **Basis for Opinion**

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. 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 RYR-1 Foundation and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. 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 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 RYR-1 Foundation's ability to continue as a going concern within 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 generally accepted auditing standards 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 generally accepted auditing standards, 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 RYR-1 Foundation'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 any conditions or events, considered in the aggregate, that raise substantial doubt about The RYR-1 Foundation'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.

Pittsburgh, Pennsylvania October 11, 2023

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# STATEMENTS OF FINANCIAL POSITION DECEMBER 31, 2022 AND 2021

<u>ASSETS</u>	2022	2021
Cash and cash equivalents Investments Pledges receivable	\$ 269,808 1,760,735 35,000	\$ 292,850 1,827,719 116,290
TOTAL ASSETS	\$ 2,065,543	\$ 2,236,859
LIABILITIES		
Credit cards payable Accrued salaries and withholdings Deferred revenue	\$ 233 3,434 	\$ 194 1,225 7,403
Total	3,667	8,822
NET ASSETS		
Without donor restrictions Without donor restrictions - Board designated With donor restrictions	1,437,902 - 623,974	1,425,000 14,300 788,737
Total	2,061,876	2,228,037
TOTAL LIABILITIES AND NET ASSETS	\$ 2,065,543	\$ 2,236,859
See accompanying notes to the financial statements.		

THE RYR-1 FOUNDATION

## STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

		20	22		2021					
	Without Donor Restrictions	Without Donor Restrictions - Board <u>Designated</u>	With Donor Restrictions	<u>Total</u>	Without Donor <u>Restrictions</u>	Without Donor Restrictions - Board <u>Designated</u>	With Donor Restrictions	<u>Total</u>		
SUPPORT AND REVENUE: Donations and contributions Family conference registration Sponsorships income Contributions - non-financial assets	\$ 172,074 21,506 - 10,156	- - -	\$ 137,899 - 24,100	\$ 309,973 21,506 24,100	\$ 134,336 - 1,800	- - -	\$ 317,746 - -	\$ 452,082 - 1,800		
Donated securities Grants Program income	10,156	- - -	21,000 -	10,156 - 21,000 -	- 44,446 - 180	- - -	- - -	44,446 - 180		
Investment activity PPP loan forgiveness income Miscellaneous income Releases from restriction	(16,983) - 315 362,062	- - - \$ (14,300)	- - - (347,762)	(16,983) - 315 -	18,942 14,130 3,439 117,236	- - - \$ (43,200)	- - - (74,036)	18,942 14,130 3,439		
Total support and revenue	549,130	(14,300)	(164,763)	370,067	334,509	(43,200)	243,710	535,019		
EXPENSES: Program Support and administrative Development	414,574 113,564 <u>8,090</u>	- - -	- - -	414,574 113,564 8,090	162,171 71,923 22,301	- - -	- - -	162,171 71,923 22,301		
Total expenses	536,228			536,228	256,395			256,395		
INCREASE (DECREASE) IN NET ASSETS	12,902	(14,300)	(164,763)	(166,161)	78,114	(43,200)	243,710	278,624		
NET ASSETS, BEGINNING OF YEAR	1,425,000	14,300	788,737	2,228,037	1,346,886	57,500	545,027	1,949,413		
NET ASSETS, END OF YEAR	<u>\$ 1,437,902</u>	<u>\$</u>	<u>\$ 623,974</u>	<u>\$ 2,061,876</u>	<u>\$ 1,425,000</u>	<u>\$ 14,300</u>	\$ 788,737	\$ 2,228,037		
See accompanying notes to the financial statements.										

THE RYR-1 FOUNDATION

## STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2022

	Family <u>Conference</u>	Research <u>Grants</u>	<u>SAB</u>	Research Workshop	Other <u>Programs</u>	Total <u>Programs</u>	Support and Administra- tive Services	Develop- ment	<u>Total</u>
Administrative support	\$ 870	\$ 10	_	\$ 260	\$ 20	\$ 1,160	\$ 1,232	\$ 510 \$	2,902
Advertising and marketing	574		-	375	-	949	45	-	994
Bank, credit card processing									
and brokerage fees	-	639	-	306	30	975	2,220	-	3,195
Business expenses	-	-	-	-	-	-	14,251	255	14,506
Education	-	-	-	-	1,565	1,565	-	-	1,565
Grants and contributions	-	186,313	-	-	-	186,313	-	-	186,313
Honorariums	-	- \$	5,000	-	-	5,000	<u>-</u>	-	5,000
Insurance	-	-	-	-	-	-	12,133	-	12,133
Legal and accounting	1,008		-	1,243	-	7,834	14,863	-	22,697
Meals and entertainment	48,798	-	-	15,625	-	64,423	-	-	64,423
Media and communications	18,412	-	-	5,591	129	24,132	20,859	-	44,991
Other program expenses	24,425	-	-	15,011	795	40,231	-	1,190	41,421
Miscellaneous	-	-	-	-	-	-	255	-	255
Office supplies	-	-	-	20	95	115	3,817	927	4,859
Payroll	13,393	2,140	2,134	10,263	4,530	32,460	38,414	3,669	74,543
Payroll taxes	1,086	177	176	667	361	2,467	3,188	303	5,958
Postage	287	-	-	-	-	287	318	896	1,501
Printing and copying	885	-	-	523	-	1,408	-	340	1,748
SIMPLE IRA match	-	-	-	-	-	· -	1,969	-	1,969
Sponsorships	-	-	-	-	875	875	-	-	875
Travel and conferences	16,414			27,966		44,380			44,380
Total expenses	\$ 126,152	\$ 194,862 \$	7,310	\$ 77,850	\$ 8,400	\$ 414,574	\$ 113,564	\$ 8,090	536,228

See accompanying notes to the financial statements.

THE RYR-1 FOUNDATION

## STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2021

	Family Conference	<u>:е</u>	Research <u>Grants</u>		<u>SAB</u>	<u>CCG</u>	<u> </u>	Other Programs	Total <u>Programs</u>	Support and Administra- tive Services		Develop- <u>ment</u>		<u>Total</u>
Administrative support	\$ 3	9 \$	53	\$	8	_	\$	2,055	\$ 2,155	\$ 12,547	\$	331	\$	15,033
Advertising and marketing	3,65		-	*	-	-	Ψ.	-,000	3,656	-	*	340	Ψ	3,996
Bank, credit card processing														
and brokerage fees	-		196		70	-		-	266	1,783		-		2,049
Business expenses	-		-		-	-		-	-	-		9,305		9,305
Education	-		-		-	-		810	810	-		-		810
Grants and contributions	-		109,585		-	-		-	109,585	-		-		109,585
Honorariums	-		-		1,500	-		-	1,500	-		-		1,500
Insurance	-		-		-	-		-	-	3,380		-		3,380
Legal and accounting	-		1,615		-	-		-	1,615	19,236		-		20,851
Media and communications	-		-		-	-		403	403	-		-		403
Other program expenses	-		251		-	\$ 16,136		-	16,387	-		-		16,387
Miscellaneous	-		-		-	-		-	-	2,352		-		2,352
Office supplies	-		-		-	-		282	282	3,427		1,517		5,226
Payroll	4,75	5	5,800		1,998	1,065		6,539	20,157	25,206		7,171		52,534
Payroll taxes	46	3	570		201	107		656	1,997	2,497		720		5,214
Postage	-		-		-	-		7	7	99		1,726		1,832
Printing and copying	-		36		-	-		-	36	-		1,191		1,227
Sponsorships	-		-		-	-		3,295	3,295	-		_		3,295
SIMPLE IRA Match	-		-		-	-		-	-	1,396		-		1,396
Travel and conferences	2	<u>.0</u>				 			20					20
Total expenses	\$ 8,93	<u>3</u> \$	118,106	\$	3,777	\$ 17,308	\$	14,047	<u>\$ 162,171</u>	\$ 71,923	\$	22,301	\$	256,395

See accompanying notes to the financial statements.

## STATEMENTS OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

	2022	<u>2021</u>
CASH FLOWS FROM OPERATING ACTIVITIES: Increase (decrease) in net assets Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities:	\$ (166,161) \$	278,624
Unrealized (gain) loss on investments Donated securities (Increase) decrease in:	41,043 -	(16,621) (44,446)
Pledges receivable Increase (decrease) in:	81,290	(103,290)
Credit cards payable Accrued salaries and withholdings Deferred revenue	39 2,209 (7,403)	(488) (186) 7,403
Net cash provided by (used in) operating activities	(48,983)	120,996
CASH FLOWS FROM INVESTING ACTIVITIES: Purchase of investments Proceeds from sale of investments	(1,014,999) 1,040,940	(368,779) 166,458
Net cash provided by (used in) investing activities	25,941	(202,321)
NET DECREASE IN CASH AND CASH EQUIVALENTS	(23,042)	(81,325)
CASH AND CASH EQUIVALENTS, BEGINNING	292,850	374,175
CASH AND CASH EQUIVALENTS, ENDING	<u>\$ 269,808</u> <u>\$</u>	292,850
See accompanying notes to the financial statements.		

## 1. ORGANIZATION, PURPOSE AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Organization, Purpose and Operations - The RYR-1 Foundation (the "Organization") is a charitable nonprofit organization whose mission is to support research leading to effective treatment or a cure for RYR-1-related diseases. They seek to achieve these goals by providing research support, physician education, and patient/family support and advocacy. Funds raised by the Organization will support both basic science and clinical research of RYR-1-related diseases (RYR-1-RD). The Organization is supported by foundation grants, government grants, & other organizations as well as individual and business contributions. The Organization does not contemplate pecuniary gain or profit, incidental or otherwise, to its members, directors, or other persons.

Financial Statement Presentation - The Organization is required to report information regarding its financial position and activities according to two classes of net assets: net assets without donor restrictions and net assets with donor restrictions. Net assets without donor restrictions are the net assets that are not restricted by donor imposed stipulations. Net assets with donor restrictions are subject to donor stipulations that either expire by the passage of time or can be fulfilled and removed by actions of the Organization pursuant to those stipulations.

The Board designated net assets that had been set aside for mice research were expended during the year ended December 31, 2022.

Use of Estimates - The preparation of financial statements in conformity with U.S. generally accepted accounting principles 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 dates of the financial statements and the reported amounts of revenues and expenses during the reporting periods. Actual results could differ from those estimates.

Cash and Cash Equivalents - The Organization considers all monies available for current use in checking, savings and certificates of deposit with initial maturities of three months or less to be cash equivalents. The Organization maintains, at financial institutions, cash which at times may exceed federally insured limits and which may at times exceed statement of financial position amounts due to outstanding checks.

Availability of Financial Assets - The Organization's financial assets available for general expenditures within one year of the statements of financial position at December 31, 2022 and 2021 are as follows:

		<u>2022</u>	<u>2021</u>
Cash and cash equivalents Pledge receivables Investments Less: Board designated - research Less: Donor restrictions	\$	269,808 35,000 1,760,735 - (623,974)	\$ 292,850 116,290 1,827,719 (14,300) (788,737)
Total	<u>\$</u>	1,441,569	\$ 1,433,822

The Organization hosts a large family conference every two years which generates a significant amount of contributions leading up to the conference. The Organization also funds various research grants to further medical advancements for RYR-1. The Organization's policy related to managing assets is to fund research grant payments, operational costs, liabilities and other obligations as they come due. Funds received specifically for research grants, clinical care guidelines and the family conferences are utilized to fund those respective expenses.

Pledges Receivable - Pledges that are expected to be collected in future years are recorded at the present value of estimated future cash flows. The pledges as of December 31, 2022 and 2021 are expected to be collected within one year. The Organization provides an allowance for uncollectible pledges based on management's evaluation of the receivable. No allowance was considered necessary at December 31, 2022 and 2021.

*Investments* - Investments in marketable securities are reflected at carrying value using quoted market prices in active markets. Investments in treasury bills are reflected at fair value. Interest (net of fees), dividends and unrealized gains and losses are included in the statements of activities.

Contributions - Contributions received are recorded as support with donor restrictions or support without donor restriction depending on the existence and/or nature of any donor restrictions. For the years ended December 31, 2022 and 2021, approximately 37% and 30%, respectively, of total support and revenue was contributed by two donors.

Revenue Recognition - Family Conference registration fees are recognized once the Family Conference has occurred. When these fees are received in advance of the period to which they apply, they are classified as deferred revenue on the statements of financial position. For the years ended December 31, 2022 and 2021, approximately 37% and 30%, respectively, of total support and revenue was contributed by two donors.

Deferred Revenue - Deferred revenue at December 31, 2021 resulted primarily from advance registration fees associated with the 2022 Family Conference. There was no deferred revenue at December 31, 2022.

Functional Expenses - Expenses are allocated based upon their functional classification as either program or supporting services. Expenses that are attributable to both program and supporting services require allocation on a reasonable basis that is consistently applied. Allocable expenses including payroll, payroll taxes, administrative support and legal are primarily allocated based on an estimate of time and effort in performing the services.

Contributed Nonfinancial Assets - Effective January 1, 2022, the Organization has adopted Financial Accounting Standards Update (ASU) 2020-07, Presentation and Disclosure by Not-for-Profit Entities for Contributed Nonfinancial Assets. The ASU requires segregation of nonfinancial assets in the statement of activities and enhances disclosures related to the description, valuation and utilization of such assets.

Contributed services and materials are recorded at fair value at the time of receipt to the extent an objective basis is available to measure the value of the services or materials. These contributions are recognized as both support and expenses or assets in the financial statements. Contributed assets, materials and services are used to advance program service by the Organization. Such amounts were not significant for the year ended December 31, 2021.

For the year ended December 31, 2022, contributed nonfinancial assets recognized within the statement of activities were as follows:

Travel Scientific Advisory Board ("SAB") Honorarium fees Professional services	\$  5,144 4,000 1,012
Total contributed non-financial assets	\$ 10,156

In addition, RYR-1 is highly dependent upon the time and effort of volunteers through fundraising and management activities. These donated services are not reflected in the financial statements since the services do not require specialized skills.

Advertising - Advertising costs are expensed as incurred. Advertising expenses were \$994 and \$3,996 for the years ended December 31, 2022 and 2021, respectively.

Fair Value Measurements - The Organization has adopted the guidance included in U.S. generally accepted accounting principles which establish a framework for measuring fair value of financial assets and expands disclosures about fair value measurements. The fair value hierarchy for disclosure of fair value measurements is as follows:

- Level 1 Quoted prices (unadjusted) in active markets for identical assets or liabilities;
- Level 2 Inputs, other than quoted prices in active markets, that are observable either directly or indirectly; and

 Level 3 - Unobservable inputs that reflect the reporting entity's own assumptions.

The Organization's assets measured at fair value consist of mutual funds, U.S. Treasury bills and a U.S. Treasury note based on their quoted prices (level 1 inputs); and money market funds, based on estimated redemption value (level 2 inputs).

The method described above may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, while the Organization believes its valuation method is 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.

Income Taxes - The Organization meets the requirements to be treated as an organization exempt from income tax under Section 501(c)(3) of the Internal Revenue Code. Accordingly, no provision for federal income tax is required.

Management believes there is no liability related to uncertain tax positions at December 31, 2022 or 2021. The Organization is no longer subject to tax examinations for the years before December 31, 2019.

Subsequent Events - The Organization has analyzed subsequent events for recognition and disclosure purposes through October 11, 2023, the date the financial statements were available to be issued.

#### 2. INVESTMENTS

Investments consisted of the following at December 31, 2022 and 2021:

		<u>2022</u>	<u>2021</u>
Cash and cash equivalents U.S. Treasury securities	\$	111,753 485,415	\$ 761,686 -
Money market funds Mutual funds		937,166 226,401	 896,844 169,189
Total	<u>\$</u>	1,760,735	\$ 1,827,719

The Organization holds three U.S. Treasury securities at December 31, 2022. The following describes the maturity date and carrying amount at December 31, 2022:

	Carrying <u>Amount</u>	Fair Value
Treasury bill - due April 27, 2023 Treasury bill - due October 5, 2023	\$ 98,594 289,837	\$ 100,000 300,000

Treasury note - due May 31, 2024 (2.5%)	\$ 96,984	<u>\$</u>	100,000
Total	\$ 485,41 <u>5</u>	\$	500,000

#### 3. NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions all of which are restricted for purpose consisted of the following at December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Research Prevalence study Restricted salaries Family conference Dr. Nicol Voerman's research Scientific meetings Fundraising dinner Research on doubly heterozygous mice	\$ 213,125 150,000 165,000 55,720 34,946 5,000 183	\$ 292,539 150,000 35,000 139,969 69,446 - 183 51,600
International Research Workshop	 	 50,000
Total	\$ 623,974	\$ 788,737

#### 4. NET ASSETS RELEASED FROM RESTRICTIONS

Net assets were released from donor restrictions by incurring expenses and satisfying the restricted purposes or by occurrence of other events specified by donors, which consisted of the following for the years ended December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Research Family conference International Research Workshop Clinical Care Guidelines: What Parents	\$ 172,012 98,250 77,500	\$ 57,026 679 -
and Families Need to Know	 	 16,331
Total	\$ 347,762	\$ 74,036

#### 5. PAYCHECK PROTECTION PROGRAM

On February 1, 2021, the Organization received a Paycheck Protection Program ("PPP") loan of \$14,130. The full amount of the loan is reflected as PPP loan forgiveness income for the year ended December 31, 2021, as the loan was fully forgiven by the Small Business Administration on September 24, 2021.