



GROSSMAN YANAK & FORD LLP
Certified Public Accountants and Consultants

THE RYR-1 FOUNDATION

**Financial Statements as of and for the Years Ended December 31,
2020 and 2019 and Independent Auditors' Report**

THE RYR-1 FOUNDATION

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INDEPENDENT AUDITORS' REPORT

To the Board of Directors
of The RYR-1 Foundation

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, 2020 and 2019, 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.

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.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditors' judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditors consider internal control relevant to the entity's preparation and fair presentation of the financial statements 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 entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

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, 2020 and 2019, 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.

Grossman Yamak + Fords LLP

Pittsburgh, Pennsylvania
November 12, 2021

THE RYR-1 FOUNDATION

STATEMENTS OF FINANCIAL POSITION DECEMBER 31, 2020 AND 2019

<u>ASSETS</u>	<u>2020</u>	<u>2019</u>
Cash and cash equivalents	\$ 374,175	\$ 325,863
Investments	1,564,331	1,522,084
Pledges receivable	13,000	50,000
Prepaid expenses	<u>-</u>	<u>10,000</u>
TOTAL ASSETS	<u>\$ 1,951,506</u>	<u>\$ 1,907,947</u>
<u>LIABILITIES</u>		
Accounts payable	-	\$ 3,200
Credit cards payable	\$ 682	7,320
Accrued salaries and withholdings	1,411	3,294
Deferred revenue	<u>-</u>	<u>6,769</u>
Total	<u>2,093</u>	<u>20,583</u>
<u>NET ASSETS</u>		
Without donor restrictions	1,346,886	1,183,502
Without donor restrictions - Board designated	57,500	57,500
With donor restrictions	<u>545,027</u>	<u>646,362</u>
Total	<u>1,949,413</u>	<u>1,887,364</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 1,951,506</u>	<u>\$ 1,907,947</u>

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, 2020 AND 2019

	2020				2019			
	Without Donor Restrictions	Without Donor Restrictions - Board Designated	With Donor Restrictions	Total	Without Donor Restrictions	Without Donor Restrictions - Board Designated	With Donor Restrictions	Total
SUPPORT AND REVENUE:								
Donations and contributions	\$ 241,822	-	\$ 41,985	\$ 283,807	\$ 260,463	-	\$ 309,224	\$ 569,687
Sponsorships income	-	-	10,000	10,000	817	-	183	1,000
Donated securities	30,846	-	-	30,846	9,854	-	-	9,854
Grants	-	-	50,000	50,000	35,000	-	50,000	85,000
Program income	248	-	-	248	340	-	-	340
Investment income	11,534	-	-	11,534	26,860	-	-	26,860
Miscellaneous income	5,296	-	-	5,296	1,497	-	-	1,497
Releases from restriction	203,320	-	(203,320)	-	37,890	-	(37,890)	-
Total support and revenue	493,066	-	(101,335)	391,731	372,721	-	321,517	694,238
EXPENSES:								
Program	247,430	-	-	247,430	213,296	\$ 2,550	-	215,846
Support and administrative	65,580	-	-	65,580	58,106	-	-	58,106
Development	16,672	-	-	16,672	22,834	-	-	22,834
Total expenses	329,682	-	-	329,682	294,236	2,550	-	296,786
INCREASE (DECREASE) IN NET ASSETS	163,384	-	(101,335)	62,049	78,485	(2,550)	321,517	397,452
NET ASSETS, BEGINNING OF YEAR	1,183,502	\$ 57,500	646,362	1,887,364	1,105,017	60,050	324,845	1,489,912
NET ASSETS, END OF YEAR	\$ 1,346,886	\$ 57,500	\$ 545,027	\$ 1,949,413	\$ 1,183,502	\$ 57,500	\$ 646,362	\$ 1,887,364

See accompanying notes to the financial statements.

THE RYR-1 FOUNDATION

STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2020

	Family Conference	Research Grants	SAB	CCG	Other Programs	Total Programs	Support and Administra- tive Services	Develop- ment	Total
Administrative support	\$ 365	\$ 113	-	\$ 570	\$ 1,725	\$ 2,773	\$ 8,784	\$ 1,783	\$ 13,340
Advertising and marketing	3,000	-	-	-	-	3,000	62	3,311	6,373
Bank, credit card processing and brokerage fees	-	146	\$ 146	-	-	292	351	-	643
Business expenses	-	-	-	-	-	-	1,776	633	2,409
Education	-	-	-	-	76	76	2,254	-	2,330
Grants and contributions	-	177,996	-	-	-	177,996	-	-	177,996
Honorariums	-	-	3,000	-	-	3,000	-	-	3,000
Insurance	-	-	-	-	-	-	2,763	-	2,763
Legal and accounting	1,274	7,184	-	130	-	8,588	13,122	-	21,710
Media and communications	-	-	-	-	40	40	908	-	948
Other program expenses	-	-	-	24,230	-	24,230	-	-	24,230
Miscellaneous	-	-	-	-	34	34	3,780	418	4,232
Office supplies	-	-	-	-	-	-	4,270	495	4,765
Payroll	2,965	3,293	3,123	8,739	4,282	22,402	24,654	7,191	54,247
Payroll taxes	301	334	317	886	434	2,272	2,502	729	5,503
Postage	-	-	-	-	-	-	354	863	1,217
Printing and copying	-	-	-	-	-	-	-	1,249	1,249
Travel and conferences	298	-	2,429	-	-	2,727	-	-	2,727
Total expenses	<u>\$ 8,203</u>	<u>\$ 189,066</u>	<u>\$ 9,015</u>	<u>\$ 34,555</u>	<u>\$ 6,591</u>	<u>\$ 247,430</u>	<u>\$ 65,580</u>	<u>\$ 16,672</u>	<u>\$ 329,682</u>

See accompanying notes to the financial statements.

THE RYR-1 FOUNDATION

STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 2019

	Family Conference	Research Grants	SAB	Other Programs	Total Programs	Support and Administra- tive Services	Develop- ment	Total
Administrative support	\$ 150	\$ 98	-	\$ 1,853	\$ 2,101	\$ 5,247	\$ 1,030	\$ 8,378
Advertising and marketing	-	-	-	-	-	135	7,634	7,769
Bank, credit card processing and brokerage fees	-	-	\$ 195	-	195	1,878	-	2,073
Business expenses	-	-	-	82	82	393	2,898	3,373
Grants and contributions	-	120,443	-	-	120,443	-	-	120,443
Honorariums	-	-	3,000	-	3,000	-	-	3,000
Insurance	-	-	-	-	-	2,693	-	2,693
Legal and accounting	160	5,365	-	-	5,525	20,785	2,540	28,850
Meals and entertainment	-	-	8,506	-	8,506	1,053	282	9,841
Media and communications	-	-	7,206	48	7,254	912	-	8,166
Miscellaneous	32	2	35	418	487	(510)	771	748
Office supplies	-	-	637	-	637	4,838	479	5,954
Payroll	8,492	8,492	11,323	8,492	36,799	16,983	2,830	56,612
Payroll taxes	723	723	964	723	3,133	1,447	241	4,821
Postage	-	59	-	130	189	146	798	1,133
Printing and copying	-	-	-	-	-	37	3,302	3,339
Sponsorships	-	-	-	8,186	8,186	-	-	8,186
Travel and conferences	<u>565</u>	<u>-</u>	<u>18,744</u>	<u>-</u>	<u>19,309</u>	<u>2,069</u>	<u>29</u>	<u>21,407</u>
Total expenses	<u>\$ 10,122</u>	<u>\$ 135,182</u>	<u>\$ 50,610</u>	<u>\$ 19,932</u>	<u>\$ 215,846</u>	<u>\$ 58,106</u>	<u>\$ 22,834</u>	<u>\$ 296,786</u>

See accompanying notes to the financial statements.

THE RYR-1 FOUNDATION

STATEMENTS OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

	<u>2020</u>	<u>2019</u>
CASH FLOWS FROM OPERATING ACTIVITIES:		
Increase in net assets	\$ 62,049	\$ 397,452
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
(Gain) loss on investments	1,125	(2,211)
Donated securities	(30,846)	(9,854)
(Increase) decrease in:		
Pledges receivable	37,000	(50,000)
Prepaid expenses	10,000	(10,000)
Increase (decrease) in:		
Accounts payable	(3,200)	(3,050)
Credit cards payable	(6,638)	(9,674)
Accrued salaries and withholdings	(1,883)	3,294
Deferred revenue	<u>(6,769)</u>	<u>6,769</u>
Net cash provided by operating activities	<u>60,838</u>	<u>322,726</u>
CASH FLOWS FROM INVESTING ACTIVITIES:		
Purchase of investments	(43,548)	(785,132)
Proceeds from sale of investments	<u>31,022</u>	<u>160,483</u>
Net cash used in investing activities	<u>(12,526)</u>	<u>(624,649)</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	48,312	(301,923)
CASH AND CASH EQUIVALENTS, BEGINNING	<u>325,863</u>	<u>627,786</u>
CASH AND CASH EQUIVALENTS, ENDING	<u>\$ 374,175</u>	<u>\$ 325,863</u>

See accompanying notes to the financial statements.

THE RYR-1 FOUNDATION

NOTES TO 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 muscle disease. The Organization is supported by foundation grants 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 have been set aside for mice research.

COVID-19 - The year ended December 31, 2020 was marked by domestic and global uncertainty surrounding the COVID-19 pandemic. The Organization was able to continue to operate throughout 2020; however, as a result of the pandemic, in early 2020, the Organization decided to postpone the Family Conference scheduled for July 2020; in May 2021 the Organization made the decision to schedule the next Family Conference in July 2022. The Organization has continued to evaluate its options under various programs.

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, 2020 and 2019 are as follows:

	<u>2020</u>	<u>2019</u>
Cash and cash equivalents	\$ 374,175	\$ 325,863
Investments	1,564,331	1,522,084
Less: Board designated - research	(57,500)	(57,500)
Less: Donor restrictions - research	(388,164)	(495,743)
Less: Donor restrictions - 2020 and 2022 Family Conferences	(140,349)	(100,436)
Less: Donor restrictions - other	<u>(16,514)</u>	<u>(50,183)</u>
Total	<u>\$ 1,335,979</u>	<u>\$ 1,144,085</u>

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, 2020 and 2019 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, 2020 and 2019.

Investments - Investments in marketable securities are reflected at fair 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. Donor-restricted income is classified as income without donor restrictions if restrictions are satisfied in the same fiscal year in which the income is received. For the year ended December 31, 2020, approximately 13% of total support and revenue was contributed by one donor. For the year ended December 31, 2019, approximately 51% 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.

Deferred Revenue - Deferred revenue at December 31, 2019 resulted primarily from advance registration fees associated with the 2020 Family Conference, which was postponed to July 2022 due to the COVID-19 pandemic. As the Family Conference was canceled, participants' registration fees were either refunded to the participant or donated to the Organization. Related expenses were presented as prepaid expenses. There was no deferred revenue at December 31, 2020.

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.

Donated Services - 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 \$6,373 and \$7,769 for the years ended December 31, 2020 and 2019, 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 equitable securities and U.S. treasury bills, 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, 2020 or 2019. The Organization is no longer subject to tax examinations for the years before December 31, 2017.

Subsequent Events - The Organization has analyzed subsequent events for recognition and disclosure purposes through November 12, 2021, the date the financial statements were available to be issued.

2. INVESTMENTS

Investments, at fair value, consisted of the following at December 31, 2020 and 2019:

	<u>2020</u>	<u>2019</u>
Cash and cash equivalents	\$ 561,471	\$ 559,426
U.S. treasury bills	-	613,627
Money market funds	970,292	349,031
Equity securities	<u>32,568</u>	<u>-</u>
Total	<u>\$ 1,564,331</u>	<u>\$ 1,522,084</u>

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, 2020 and 2019:

	<u>2020</u>	<u>2019</u>
Research	\$ 336,564	\$ 444,143
Family Conference	140,349	100,436
Research on doubly heterozygous mice	51,600	51,600
Clinical Care Guidelines: What Parents and Families Need to Know	16,331	50,000
Fundraising dinner	<u>183</u>	<u>183</u>
Total	<u>\$ 545,027</u>	<u>\$ 646,362</u>

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, consisted of the following for the years ended December 31, 2020 and 2019:

	<u>2020</u>	<u>2019</u>
Research	\$ 165,079	\$ 37,133
Family Conference	4,572	757
Clinical Care Guidelines: What Parents and Families Need to Know	<u>33,669</u>	<u>-</u>
Total	<u>\$ 203,320</u>	<u>\$ 37,890</u>

5. PAYCHECK PROTECTION PROGRAM

On February 1, 2021, the Organization received a Paycheck Protection Program ("PPP") loan of \$14,130. Management expects that all or substantially all of this amount will be forgiven in accordance with the terms of the program.
