# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.

FINANCIAL STATEMENTS YEAR ENDED SEPTEMBER 30, 2022 (With Comparative Totals for 2021)

Prepared by Francis S. Infurchia & Company, LLC March 18, 2023



# **Certified Public Accountants**

Francis S. Infurchia, CPA Lawrence J. Silvestro, CPA Francis S. Infurchia, Jr., CPA

### INDEPENDENT AUDITORS' REPORT

To the Board of Directors

Foundation for Ichthyosis and Related Skin Types, Inc.

# Opinion

We have audited the accompanying financial statements of Foundation for Ichthyosis and Related Skin Types, Inc. (a nonprofit organization), which comprise the statement of financial position as of September 30, 2022, and the related statements of activities, functional expenses, and cash flows for the year 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 Foundation for Ichthyosis and Related Skin Types, Inc. as of September 30, 2022, and the changes in net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

# **Basis for Opinion**

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. 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 Foundation for Ichthyosis and Related Skin Types, Inc. 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 Foundation for Ichthyosis and Related Skin Types, Inc.'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 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 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 Foundation for Ichthyosis and Related Skin Types, Inc.'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 Foundation for Ichthyosis and Related Skin Types, Inc.'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.

# Report on Summarized Comparative Information

We have previously audited Foundation for Ichthyosis and Related Skin Types, Inc.'s 2021 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated August 15, 2022. In our opinion, the summarized comparative information presented herein as of and for the year ended September 30, 2021, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Angurchia + Cinpuny, LLC

Francis S. Infurchia & Company, LLC

Norwalk, CT March 18, 2023

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF FINANCIAL POSITION SEPTEMBER 30, 2022 (WITH COMPARATIVE TOTALS FOR 2021)

		2022	-	2021
ASSETS				
Current assets				
Cash and cash equivalents	\$	191,700	\$	179,817
Short term Investments		1,578,261		2,247,536
Prepaid expenses		3,624		30,583
Total current assets		1,773,585		2,457,936
Non current assets				
Investments, with donor restrictions		160,512		110,013
Property and equipment at cost,				
net of accumulated depreciation		24,505		32,767
Other assets				
Deposits		_		15,000
Total non current assets		185,017		157,780
Total assets	\$	1,958,602	\$	2,615,716
LIABILITIES AND NET	ASSE	TS		
Current liabilities				
Accounts payable and accrued expenses	\$	32,271	\$	30,057
Net Assets				
Without donor restrictions				
Undesignated		879,661		1,577,358
Board designated		164,294		168,929
Net assets without donor restrictions		1,043,955		1,746,287
With donor restrictions				
Temporarily		721,864		729,359
Permanently		160,512		110,013
Net assets with donor restrictions		882,376		839,372
Total net assets		1,926,331	***************************************	2,585,659
Total liabilities and net assets	\$	1,958,602	\$	2,615,716

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.
STATEMENT OF ACTIVITIES AND CHANGES TO NET ASSETS
FOR THE YEAR ENDED SEPTEMBER 30, 2022
(WITH COMPARATIVE TOTALS FOR 2021)

				2	2022					
	With	Without Donor Restrictions	Ter	Temporarily Restricted	Peri	Permanently Restricted		Total		2021 Totals
Support and operating revenue Contributions Net assets released from restrictions	₩	455,775	₩	113,173 (120,668)	₩.	50,499		619,447	↔	602,335
Total support and revenue		576,443		(7,495)		50,499		619,447		602,335
Operating expenses: Program services		695,120		1		ı		695,120		438,302
Supporting services.  Management and general  Fundraising		112,637		1 1		1 1		112,637		116,705
Total operating expenses		891,681				,		891,681		626,248
Change in net assets before non-operating revenues and expenses		(315,238)		(7,495)		50,499		(272,234)		(23,913)
Non-operating activities Investment income (loss) PPP loan forgiveness income		(387,094)			,	1 1 1		(387,094)		329,306 95,950 425,256
Change in net assets	❖	(702,332)	↔	(7,495)	↔	50,499	↔	(659,328)	₩	401,343
Net assets, beginning of year		1,746,287		729,359		110,013		2,585,659		2,184,316
Net assets, end of year	φ.	1,043,955	\$	721,864	❖	160,512	❖	1,926,331	₩	2,585,659

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED SEPTEMBER 30, 2022 (WITH COMPARATIVE TOTALS FOR 2021)

				2022	2					
	4	Program Services	Man	Management and General	Fun	Fundraising		Total		2021
Salaries, payroll taxes and other	'		3	5		0				
related costs	\$	248,867	\$	42,017	❖	32,320	s	323,204	↔	318,431
Bank charges		443		8,412		1		8,855		6,964
ookkeeping and administrative		23,511		7,405		6,109		37,025		38,211
Consultant - support and development		30,874		9,724		8,022		48,620		47,813
Conferences and meetings		4,449		1,401		1,156		2,006		4,281
Depreciation		826		6,610		826		8,262		12,686
Dues and subscriptions		2,071		652		538		3,261		2,828
Insurance - general and health		12,421		3,912		3,227		19,560		25,435
Investment fees		1,250		10,000		1,250		12,500		11,687
Licenses		3,188		1,004		828		5,020		7,797
National conference and events		226,329		•		11,912		238,241		ı
Office expense and supplies		7,021		2,211		1,825		11,057		7,492
Patient support forums		ı		•		ı		1		200
stage and shipping		5,322		1,676		1,383		8,381		099'9
Printing and publications		12,943		4,077		3,363		20,383		23,565
Professional fees		16,142		5,084		4,195		25,421		18,940
Publishing		3,295		1		ı		3,295		1
Rent and utilities		802		253		208		1,263		2,904
holarship awards		19,336		1		1		19,336		13,556
Strategic initiatives - research		20,000		,		f		50,000		20,000
lephone		2,145		9/9		557		3,378		2,296
Technology and software		14,052		4,426		3,651		22,129		16,660
avel		4,061		1,279		1,055		6,395		1
Website management		5,772		1,818		1,499		680'6		7,542
Total operating expenses	<b>ب</b>	695,120	\$	112,637	\$	83,924	\$	891,681		
Total 2021 operating expenses	\$	438,302	\$	116,705	\$	71,241			\$	626,248

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF CASH FLOWS FOR THE YEAR ENDED SEPTEMBER 30, 2022 (WITH COMPARATIVE TOTALS FOR 2021)

	2022	2021
Cash flows from operating activities		Street Control
Change in net assets	\$ (659,328)	\$ 401,343
Adjustments to reconcile change in net assets		
to net cash provided by (used in) operating activities:		
Depreciation	8,262	12,686
Net realized and unrealized loss (gain) on investments	484,182	(257,664)
Donated stock	(127,736)	(47,054)
Changes in operating assets and liabilities:		
(Increase) decrease in:		
Prepaid expense	26,959	4,174
Deposits	15,000	3,000
(Decrease) increase in:		
Accounts payable and accrued expenses	2,214	(42,017)
Net cash provided by (used in) operating activities	(250,447)	74,468
Cash flows used for investing activities		
Net proceeds from sale (purchase) of investments	60,361	12,862
Net transfer (to) from investment accounts	345,000	75,000
Reinvestment of dividends	(97,080)	(71,642)
Purchase of fixed assets	-	(6,342)
Net cash (used in) provided by investing activities	308,281	9,878
Cash flows from financing activities		
Forgiveness of Paycheck Protection Program Loan	(45,951)	(45,951)
Net cash (used in) provided by financing activities	(45,951)	(45,951)
Net change in cash and cash equivalents	11,883	38,395
Cash and cash equivalents - beginning of the year	179,817	141,422
Cash and cash equivalents - end of year	\$ 191,700	\$ 179,817
Supplemental Information:		
Cash paid for interest	\$ -	\$ -
Cash paid for income taxes	Č	<u> </u>
Cash palu for income taxes	٠ 	<b>-</b>

### 1. NATURE OF ORGANIZATION

The Foundation for Ichthyosis and Related Skin Types (the Foundation) was incorporated in the State of California on January 2, 1981. The Foundation is an organization offering information, education, and support services to its global membership of persons affected with ichthyosis and other related skin conditions and their families.

The Foundation serves as a hub connecting patients, caregivers, the healthcare community, and others seeking better treatments and potential cures. The Foundation's website, Medical and Scientific Advisory Board and knowledgeable community are an invaluable resource to parents of newborn children diagnosed with ichthyosis as well as adults and others seeking better treatments.

The Foundation communicates regularly with its constituents through twice annually published newsletters, twice monthly electronic newsletters, virtual and in-person meetups and social media. The Foundation promotes research through direct funding and by marketing opportunities to participate in quality-of-life studies and clinical trials.

In June 2022, after a two-year delay due to the Coronavirus pandemic, the Foundation resumed its biannual national conference in Providence, Rhode Island. The conference had 373 participants which included 63 families with affected children, 57 affected adults, and 29 medical professionals and researchers.

# 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 accounting principles generally accepted in the United States of America ("GAAP").

In the statement of financial position, assets and liabilities are presented in order of liquidity or conversion to cash and their maturity resulting in the use of cash, respectively.

# **Basis of Presentation**

The financial statement presentation follows the recommendations of the Financial Accounting Standards Board ("FASB") Accounting Standards Codification ("ASC") 958-205, Presentation of Financial Statements. As amended by Accounting Standards Update No. 2016-14, the Foundation is required to report information regarding its financial position and activities according to two classes of net assets:

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. In total, the Foundation had \$1,043,955 in net assets without donor restrictions.

Net assets with donor restrictions: Net assets subject to stipulations imposed by donors and grantors. Some donor restrictions are temporary in nature; those restrictions will be met by actions of the Foundation or by the passage of time. Other donor restrictions are perpetual in nature, whereby the donor has stipulated the funds be maintained in perpetuity. At September 30, 2022, the Foundation had

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

# **Basis of Presentation (Continued)**

net assets with restrictions which are perpetual in nature in the amount of \$160,512. In total, the Foundation had \$882,376 in net assets with donor restrictions at September 30, 2022.

# **Designated Net Assets**

Periodically, the Board may designate a portion of the Foundation's net assets for specified long-term expenditures. These designations aid in meeting the Foundation's long-term objectives and assist in the prudent management of its assets. The Board has the authority to change or modify its own actions as circumstances merit. At September 30, 2022, the Foundation had \$164,294 of Board designated net assets — a subset of net assets without outside donor-imposed restrictions.

# **Accounting Pronouncement**

In 2016, FASB issued ASU 2016-14, *Not-for-Profit Entities (Topic 958) — Presentation of Financial Statements of Not-for-Profit Entities.* The FASB update addresses the complexity and understandability of net asset classification, deficiencies in information about liquidity and availability of resources, and lack of consistency in the type of information provided about expenses and investment return. The Foundation adopted the new standard effective September 30, 2019.

# **Accounting Pronouncement Issued but Not Yet Adopted**

In February 2016, the FASB issued ASU 2016-02, *Leases (Topic 842)*, to increase transparency and comparability among organizations by recognizing lease assets and lease liabilities on the statement of financial position and disclosing key information about leasing arrangements for lessees and lessors. The new standard applies a right-of-use (ROU) model that requires, for all leases with a lease term of more than 12 months, an asset representing its right to use the underlying asset for the lease term and a liability to make lease payments to be recorded. On May 20, 2020 the FASB voted to defer the effective date of ASC 842. The ASU is effective for the Foundation's annual period's beginning after December 15, 2021, which is for the Foundation's year ended September 30, 2023, with early adoption permitted. Management does not expect this ASU to have a significant impact on the Foundation's combined financial statements.

# **Contributions Receivable and Grants and Revenue Recognition**

Contributions are recognized as revenue when an unconditional promise to give has been made. Conditional contributions, including conditional promises to give, are not recognized until they become unconditional.

All contributions and grants are considered to be without donor restrictions unless specifically restricted by the donor or grantor. Amounts received that are designated for future periods or restricted by the donor or grantor for specific purposes are reported as net assets with donor restrictions that increases that net asset class. 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.

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

# Contributions Receivable and Grants and Revenue Recognition (Continued)

There are no unconditional promises to give at September 30, 2022.

# **Measure of Operations**

Transactions deemed by management to be directly related to the programs of the Foundation are reported as operating revenues and expenses. Non-operating activities consist of gifts-in-kind, contributions, dividend and interest income, and realized and unrealized capital gains.

### Income Taxes

The Foundation is exempt from income tax under Section 501(c)(3) of the Internal Revenue Code. In addition, the Foundation has been classified as an entity that is not a private foundation within the meaning of Section 509(a) and qualifies for deductible contributions as provided in Section 170(b)(I)(A)(vi). Accordingly, no provision is required to be made for income taxes in the financial statements. There was no unrelated business income for the year ended September 30, 2022. The Foundation has filed for and received income tax exemptions in the jurisdictions where it is required to do so, i.e. the Bureau of Charitable Organizations of the Commonwealth of Pennsylvania. Additionally, the Foundation has filed Internal Revenue Service Form 990, Return of Organization Exempt From Income Tax, as required.

GAAP requires the evaluation of tax positions taken or expected to be taken in the course of preparing the Foundation's tax return to determine whether the tax positions are more likely than not of being sustained by the applicable tax authority. Tax positions not deemed to meet the more likely than not threshold would be recorded as a tax benefit or expense in the current year. A reconciliation is not provided herein, as the beginning and ending amounts of unrecognized benefits are zero, with no interim additions, reductions, or settlements. That is, the Foundation does not have any uncertain tax positions and associated unrecognized benefits that materially impact the financial statements or related disclosures. The Foundation is relying on its tax-exempt status and its adherence to all applicable laws and regulations to preserve that status. However, the conclusions regarding accounting for uncertainty in income taxes will be subject to review and may be adjusted at a later date based on factors including, but not limited to, ongoing analysis of tax laws, regulations, and interpretations thereof.

The Foundation's informational returns filed with the Internal Revenue Service are generally subject to examination for three years after the later of the due date or date of filing. However, the Foundation is not currently under audit nor has the Foundation been contacted by any of the taxing authorities.

# **Cash and Cash Equivalents**

For the purposes of the statement of cash flows, the Foundation considers all demand deposits, money market funds, and securities with original maturities of three months or less to be cash equivalents.

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

# Property, Equipment and Depreciation and Amortization

Property and equipment are recorded at cost, or if donated, at approximate fair value at the date of donation. The Foundation capitalizes property and equipment if its value is greater than \$500 and its useful life is more than one year. When assets are retired or otherwise disposed of, the cost and related depreciation are removed from the books and any resulting gain or loss is reflected in income for the period.

Depreciation is computed using the straight-line method over the estimated useful lives of the assets as follows:

Computers, printers, and website - 5 years

Furniture and fixtures - 7–10 years

Office equipment - 10 years

Leasehold improvements - shorter of the remaining term of lease or life of asset

Property and equipment consist of the following for the year ended September 30, 2022:

	Д	mounts
Computer equipment and software	\$	15,055
Website		64,510
Total property and equipment		79,565
Less: accumulated depreciation and amortization		(55,061)
Property and equipment net of accumulated depreciation		
and amortization	\$	24,505

Depreciation and amortization expense, relating to property and equipment, charged to operations was \$8,262 for the year ended September 30, 2022.

# **Donated Services and Other In-Kind Contributions**

Contributed professional services are recorded at the fair value of the services provided by professional volunteers if the services create or enhance non-financial assets and/or require specialized skills that are provided by individuals possessing those skills and would typically need to be purchased if not provided by donation. There were no contributed professional services for the year ended September 30, 2022.

The Foundation also receives donated services from unpaid volunteers who perform a variety of tasks that support the Foundation's activities. However, no amounts have been reflected in the financial statements as these services do not meet the criteria for revenue recognition under GAAP.

# **Advertising**

The Foundation follows the policy of charging the costs of advertising to expense as incurred. There were no advertising expenses for the year ended September 30, 2022.

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

# **Functional Allocation of Expenses**

The costs of providing the programs and other activities have been summarized on a functional basis in the statements of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited. Expenses that can be identified with specific programs and support services are allocated directly to their natural expense classification. Expenses relating to more than one function are allocated to program and support services based on estimates made by management, including estimates of time spent by personnel between functions and related expenses incurred for the program and supporting services benefited. Therefore, certain employee salaries, payroll taxes, and other related costs are allocated on the time spent by classification by the employee. Management and general expenses include those expenses that are not directly identifiable with any other specified function but provide for the overall support and direction of the Foundation.

A breakdown of the functional expenses for the year ended September 30, 2022 consists of:

				2022			
	2	Progran	n Services				
	Advocacy	Conference/ PSF	Education / Programs	Research	Management and General	Fundraising	Total
Salaries, payroll taxes and other related costs	\$27,375	\$64,705	\$146,832	\$9,955	\$ 42,017	\$32,320	\$323,204
Bank charges	49	115	261	18	8,412	-	8,855
Bookkeeping and administrative	2,586	6,113	13,872	940	7,405	6,109	37,025
Consultant - support and development	3,396	8,027	18,216	1,235	9,724	8,022	48,620
Conferences and meetings	489	1,157	2,625	178	1,401	1,156	7,006
Depreciation	91	215	487	33	6,610	826	8,262
Dues and subscriptions	228	538	1,222	83	652	538	3,261
Insurance - general and health	1,366	3,230	7,328	497	3,912	3,227	19,560
Investment fees	137	325	738	50	10,000	1,250	12,500
Licenses	350	829	1,881	128	1,004	828	5,020
National conference and events	24,896	58,846	133,534	9,053	-	11,912	238,241
Office expense and supplies	772	1,826	4,142	281	2,211	1,825	11,057
Postage and shipping	585	1,384	3,140	213	1,676	1,383	8,381
Printing and publications	1,424	3,365	7,636	518	4,077	3,363	20,383
Professional fees	1,775	4,197	9,524	646	5,084	4,195	25,421
Publishing	362	857	1,944	132	-	-	3,295
Rent and utilities	88	209	473	32	253	208	1,263
Scholarship awards	2,127	5,027	11,408	774	-	-	19,336

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

# **Functional Allocation of Expenses (Continued)**

	Advocacy	Conference/ PSF	Education / Programs	Research	Management and General	Fundraising	Total
Strategic initiatives - research	5,500	13,000	29,500	2,000	-	-	50,000
Telephone	236	558	1,265	86	676	557	3,378
Technology and software	1,546	3,653	8,291	562	4,426	3,651	22,129
Travel	447	1,056	2,396	162	1,279	1,055	6,395
Website management	635	1,501	3,405	231	1,818	1,499	9,089
Total operating expenses	\$76,460	\$180,733	\$410,120	\$27,807	\$112,637	\$83,924	\$891,681

### **Use of Estimates**

The preparation of financial statements in accordance with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

# **Compensated Absences**

Employees of the Foundation are entitled to paid vacation, sick days, and personal days off. As of September 30, 2022, the amount of compensation for future absences is \$2,862. Accordingly, the liability has been recorded and included in accrued expenses.

# **Comparative Financial Information**

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with accounting principles generally accepted in the United States of America. Accordingly, such information should be read in conjunction with the Foundation's financial statements for the year ended September 30, 2021, from which the summarized information was derived.

# Investments

Investments in marketable securities are reported at fair value. Fair value is determined from quoted market prices. Unrealized gains and losses are included in the change in net assets. Investment income is reported as an increase in unrestricted net assets. The Foundation's investments in marketable securities are subject to market risk. The degree and concentration of risk varies by the type of investment.

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

# **Investments (Continued)**

The following table shows unrestricted (\$1,578,261) and restricted Investments (\$160,512) held by the Foundation as of September 30, 2022:

Mutual funds – fixed income	\$	54,009
Exchange traded funds – fixed income		14,916
Mutual funds – equity	1	1,280,796
Exchange traded funds – equity		389,052
Total investments	\$ :	1,738,773

The following table shows investment income including money market earnings for the year ended September 30, 2022:

Dividends and interest	\$ 97,088
Realized losses	(7,984)
Unrealized losses	(476,198)
Total investment income	\$ (387,094)

The Foundation's investments have been approved by the Board of Directors in accordance with its investment policy. The primary investment objective of the Foundation is to provide increased yield and long-term growth of capital to meet the future obligations of the Foundation, with a secondary objective of providing the necessary income to meet the current operational needs. Thus, the long-term objective of the Foundation's investment of funds is to maximize the real return, or the nominal return less inflation, of the assets over a complete market cycle with emphasis on preserving capital and reducing volatility through prudent diversification. Realized gains and losses are computed using the average cost method and are netted with the unrealized gains and losses on the Statement of Activities. Investment earnings for year ending September 30, 2022 are included in net assets without donor restrictions.

### Statement Reclassifications

Certain reclassifications may have been made in the prior year's amounts to conform with current year statement presentation.

### 3. FAIR VALUE MEASUREMENTS

FASB ASC 820, Fair Value Measurement, specifies a hierarchy of valuation techniques based upon whether the inputs to those valuation techniques reflect assumptions other market participants would use based upon market data obtained from independent sources (observable inputs). In accordance with FASB ASC 820, the following summarizes the fair value hierarchy:

<u>Level 1 Inputs</u>—Unadjusted quoted market prices for identical assets and liabilities in an active market that the Foundation has the ability to access. Valuations of these instruments do not require a high degree of judgment since the valuations are based on quoted prices in active markets.

# 3. FAIR VALUE MEASUREMENTS (Continued)

<u>Level 2 Inputs</u>—Quoted prices for similar assets or liabilities in active markets; quoted prices for identical or similar assets or liabilities that are not active; and inputs other than quoted prices that are observable, such as models or other valuation methodologies. Valuations in this category are inherently less reliable than quoted market prices due to the degree of subjectivity involved in determining appropriate methodologies and the applicable underlying assumptions.

<u>Level 3 Inputs</u>—Inputs based on prices or valuation techniques that are both unobservable and significant to the overall fair value measurements. These inputs require significant management judgment or estimation. These financial instruments have inputs that cannot be validated by readily determinable market data and generally involve considerable judgment by management. FASB ASC 820 requires the use of observable market data, when available, in making fair value measurements.

When inputs used to measure fair value fall within different levels of the hierarchy, the level within which the fair value measurement is categorized is based on the lowest level input that is significant to the fair value measurement.

As of September 30, 2022, none of the non-investment assets and liabilities were required to be reported at fair value on a recurring basis. Carrying values of non-derivative financial instruments, including cash and cash equivalents, investments, accounts payable and accrued liabilities and other payables, approximated their fair values due to the short-term nature of these financial instruments. There were no changes in methods or assumptions during the year ended September 30, 2022.

The following table shows the investments measured at fair value at September 30, 2022, grouped by the fair value hierarchy:

	Quoted prices in active markets for identical	Quoted Prices in Markets that are not level 1 for similar assets	Significant unobservable inputs	
Description	assets (Level 1)	(Level 2)	(Level 3)	Total
Total at fair value	\$ 1,738,773	\$ -	\$ -	\$ 1,738,773

### 4. CONCENTRATIONS AND RISK

Financial instruments that potentially subject the Foundation to concentrations of credit risk consist primarily of cash and cash equivalents, and investments. The Foundation maintains its cash accounts at a commercial bank which at times exceeds federally insured limits. The Federal Deposit Insurance Corporation ("FDIC") insures \$250,000 for substantially all depository accounts. At September 30, 2022, there were no amounts in excess of insured limits. The Foundation performs ongoing evaluations of this commercial bank account to limit its concentration of risk exposure.

The Foundation also maintains cash funds, mutual funds, and investment securities with its custodian, Sun Trust Bank. These funds are not deposits or obligations of, or guaranteed by the investment company

# 4. CONCENTRATIONS AND RISK (Continued)

or any other bank or depository institution and the amount is not insured by the Federal Depository Insurance Corporation (FDIC) or any other federal, state or government agency. The balance of the cash funds and mutual funds/investment securities at September 30, 2022 was \$75,175 and \$1,738,773, respectively.

Recent market conditions have resulted in an unusually high degree of volatility and increased risks and has affected the short-term liquidity associated with certain investments held by the Foundation. As of September 30, 2022, the Foundation has unrealized losses on investments of \$476,198.

# 5. OPERATING LEASES

In October 2020, the Foundation's lease of office space ended. The Foundation moved to a remote work model for its staff.

The Foundation rents a storage unit in a self-storage facility to store equipment and supplies. Rent expense for the storage unit included in the accompanying statement of functional expenses was \$1,263.

### 6. MAJOR CONTRIBUTORS AND GRANTORS

The Foundation defines a significant contribution as greater than 10% of total support and revenue. During 2022, the Foundation did not receive any contributions or grants from a single donor greater than 10% of total support and revenue.

### 7. LIQUIDITY AND AVAILABILITY OF RESOURCES

The Foundation is principally supported by public donations, corporate and private grants, and an endowment. The goal of the Foundation is to maintain available financial assets to meet next year's operating expenses of approximately \$654,000. In the event of unanticipated liquidity needs, the Foundation has the ability to scale-back and reduce non-essential support services.

The following represents the Foundation's financial assets as of September 30, 2022 that are allowable to meet cash needs for operating expenditures within one year:

Cash and cash equivalents	\$ 191,700
Investments	1,738,773
Total financial assets	1,930,473
Less:	
-accounts payable at September 30, 2022	(32,271)
-net assets with donor restrictions	(886,883)
Financial assets available to meet general expenditures	
within one year	\$ 1,011,319

### 8. NET ASSETS WITH DONOR RESTRICTIONS AND ENDOWMENTS

Changes in net assets with donor restrictions for the year ended September 30, 2022 are as follows:

	В	eginning					E	nding
		Balance	Α	dditions	R	Releases	В	alance
Temporarily restricted:								
Diya and Aliya's Friends (DAF)	\$	4,236	\$	1,727	\$	4,886	\$	1,077
Strategic Initiatives		58,052		62,594		56,178		64,468
Research		667,071		48,852		59,604		656,319
Total Temporarily restricted	\$	729,359	\$ 2	113,173	\$ 12	20,668	\$	721,864
Permanently restricted								,
(Endowments):								
Membership assistance program		10,000		50,499		-		60,499
Research		100,013		-		-		100,013
Total Permanently restricted	\$	110,013	\$	50,499		-	\$	160,512
Total net assets with donor								A CONTRACTOR OF THE CONTRACTOR
restrictions	\$	839,372	\$	163,672	\$ 12	20,668	\$	882,376

The restricted assets will be released when expenses for the restricted purpose occur.

Permanently restricted net assets are maintained in perpetuity. The donors of these assets permit the Foundation to use all or part of the income earned for general or specific purposes.

The Foundation's endowment consists of four donor-restricted funds, Edna and Myron Curl Endowment, Milstone General Research Endowment, Jane Bukaty Membership Assistance Fund, and The Weary Fund for FIRST which were established for research and member assistance. Net assets associated with endowment funds are classified and are reported based on the existence of donor-imposed restrictions, and more specifically classified as permanently restricted assets.

Interpretation of relevant law: The Foundation's governing board has interpreted the Uniform Prudent Management of Institutional Funds Act (UPMIFA) enacted in the State of California as requiring the preservation of the fair value of the original gift as of the gift date of the donor-restricted endowment funds absent explicit donor stipulations to the contrary. As a result of this interpretation, the Foundation classifies as permanently restricted net assets (a) the original value of the gifts donated to the permanent endowment, (b) the original value of subsequent gifts to the permanent endowment, and (c) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is passed to the fund.

The remaining portion of the donor-restricted endowment fund that is not classified as permanently restricted net assets is classified as temporarily restricted net assets until those amounts are appropriated for expenditure by the Foundation in a manner consistent with the standard of prudence prescribed by UPMIFA.

# 8. NET ASSETS WITH DONOR RESTRICTIONS AND ENDOWMENTS (Continued)

In accordance with UPMIFA the Foundation considers the following factors in making a determination to appropriate or accumulate donor-restricted endowment funds:

- 1. The duration and preservation of the endowment fund
- 2. The purposes of the Foundation and the donor-restricted endowment fund
- 3. General economic conditions
- 4. The possible effect of inflation and deflation
- 5. The expected total return from income and appreciation of investments
- 6. Other resources of the Foundation
- 7. The investment policies of the Foundation

Spending Policy, Return Objectives and Risk Parameters: The Foundation has adopted investment and spending policies for endowment assets that attempt to provide a predictable stream of funding to the program supported by its endowment while seeking to maintain the purchasing power of the endowment assets.

Corpus of the endowment asset is held in perpetuity for Edna and Myron Curl Endowment, Milstone General Research Endowment, Jane Bukaty Membership Assistance Fund, and The Weary Fund for FIRST based on donor-restriction. The endowment asset is invested in a mix of equity and fixed income securities. Investment earnings on the Edna and Myron Curl and Milstone General Research Endowments is appropriated to research and will be spent when the Foundation's board of directors determine enough interest has accumulated to a level that will enable them to provide research grants. Earnings on the Jane Bukaty Membership Assistance Fund are used to provide financial assistance to families with one or more affected individuals who's financial and reimbursement circumstances make obtaining adequate care and treatment difficult or impossible. Earnings on The Weary Fund for FIRST are used to provide financial assistance to families or individuals affected with Ichthyosis or a related skin type to purchase window air conditioners.

### 9. SUBSEQUENT EVENTS

The Foundation's management has performed subsequent events procedures through March 18, 2023, which is the date the financial statements were available to be issued. There were no subsequent events requiring adjustment to the financial statements or disclosures as stated herein.