## FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.

FINANCIAL STATEMENTS
YEAR ENDED SEPTEMBER 30, 2020
(With Comparative Totals for 2019)



### **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.

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, 2020, and the related statements of activities, functional expenses, and cash flows for the year 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 the 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.

### **Auditor's Responsibility**

Our responsibility is to express an opinion on these combined 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 audit to obtain reasonable assurance about whether the combined financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the combined financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the combined financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal controls relevant to the entity's preparation and fair presentation of the combined 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 controls. 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 combined 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 Foundation for Ichthyosis and Related Skin Types, Inc. as of September 30, 2020, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

### **Other Matter**

The financial statements of the prior period were audited by a predecessor auditor. The predecessor auditor's report dated August 16, 2020, expressed an unmodified audit opinion.

### **Report on Summarized Comparative Information**

In our opinion, the summarized comparative information presented herein as of and for the year ended September 30, 2019, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Anfurchia + Company, LLC

Francis S. Infurchia & Company, LLC

Norwalk, CT October 25, 2021

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF FINANCIAL POSITION SEPTEMBER 30, 2020 (WITH COMPARATIVE TOTALS FOR 2019)

		2020		2019						
ASS	ETS									
Current assets										
Cash and cash equivalents	\$	141,422	\$	206,512						
Investments		1,959,038		1,901,946						
Prepaid expenses		34,757		1,969						
Deposit - website		_		29,699						
Total current assets		2,135,217		2,140,126						
Non current assets										
Investments, with donor restrictions		110,013		110,013						
Property and equipment at cost,										
net of accumulated depreciation		39,111		17,292						
Other assets										
Deposits		18,000		8,000						
Total non current assets		167,124		135,305						
Total assets	\$	2,302,341	\$	2,275,431						
LIADULTIES AND NET ASSETS										
LIABILITIES AND NET ASSETS										
Liabilities										
Current liabilities	ć		خ	520						
Deferred income	\$	72.074	\$							
Accounts payable and accrued expenses		72,074		95,185						
Total current liabilities		72,074		95,705						
Non current liabilities										
SBA PPP loan payable	and the sales of t	45,951		-						
Total Liabilities		118,025		95,705						
Net Assets										
Without donor restrictions										
Undesignated		1,143,981		1,073,227						
Board designated		172,139		180,682						
Total without donor restrictions		1,316,120		1,253,909						
With donor restrictions										
Temporarily		758,183		815,804						
Permanently		110,013		110,013						
Total with donor restrictions		868,196		925,817						
Total net assets		2,184,316		2,179,726						
Total liabilities and net assets	\$	2,302,341	\$	2,275,431						

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF ACTIVITIES FOR THE YEAR ENDED SEPTEMBER 30, 2020 (WITH COMPARATIVE TOTALS FOR 2019)

				2	2020					
	With	Without Donor	Ter	Temporarily Restricted	Perr	Permanently Restricted		Total		2019 Totals
Support and operating revenue										
Contributions	\$	346,452	↔	149,438	\$	•	\$	495,890	<b>ب</b>	527,211
Net assets released from restrictions		207,059		(207,059)		ı		•		-
Total support and revenue	\$	553,511	<b>ب</b>	(57,621)	<b>ب</b>	1	ν.	495,890	\$	527,211
Operating expenses:										
Program services		528,246		t		1		528,246		400,512
Supporting services: Management and general		80.078		1		1		80.078		77,279
Fundraising		45,627		Ι		1		45,627		45,268
Total operating expenses		653,951		1		ı		653,951		523,059
Change in net assets before non-operating revenues and expenses		(100,440)		(57,621)		1		(158,061)		4,152
Non-operating activities Investment income		163,045				1		163,045		83,022
Loss on disposal of assets		(394)		ŧ		-	i	(394)		I
		162,651				1		162,651		83,022
Change in net assets		62,211		(57,621)		ı		4,590		87,174
Net assets, beginning of year		1,253,909		815,804		110,013		2,179,726		2,092,552
Net assets, end of year	\$	1,316,120	\$	758,183	\$-	110,013	↔	2,184,316	↔	2,179,726

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED SEPTEMBER 30, 2020

JITH COMPARATIVE TOTALS FOR 2019)	
(WITH COMPARAT	

2020

Salaries, payroll taxes and other related costs Bank charges	<i>U</i>		-			Augusta		Total	2019 Totals
Salaries, payroll taxes and other related costs Bank charges	)	Services	and	and General	핊	Fundraising		3	
related costs Bank charges									
Bank charges	\$	180,225	\$	24,686	\$	17,378	❖	222,289	\$ 233,719
		7,093		887		887		8,867	6,485
Bookkeeping and administrative		21,161		20,094		4,584		45,839	4,598
Conferences		11,969		1		1		11,969	37,814
Depreciation		5,989		749		749		7,487	6,425
Dues and subscriptions		1,830		229		229		2,288	7,570
Grassroots		•		1		ı		1	28,897
Insurance		8,526		1,066		1,066		10,658	2,701
Interim Director		59,644		3,706		3,705		67,055	ı
Investment fees		1		11,633		,		11,633	11,019
Licenses		3,522		440		440		4,402	5,984
Office expense and supplies		6,259		782		782		7,823	8,403
Postage and shipping		10,622		1,327		1,328		13,277	10,122
Printing and publications		38,841		1,730		1,730		42,301	10,510
Professional fees		17,460		2,182		2,182		21,824	36,964
Recruitment		44,799		2,600		2,600		55,999	•
Rent and utilities		19,844		2,480		2,480		24,804	23,405
Scholarship awards		20,561		1		1		20,561	16,475
Strategic initiatives		20,000		1		ı		50,000	51,806
Telephone		2,402		300		300		3,002	2,924
Technology		13,934		1,742		1,742		17,418	12,174
Website management		3,565		445		445		4,455	5,064
Total operating expenses	\$	528,246	\$	80,078	\$	45,627	Ş	653,951	
Total 2019 operating expenses	φ	400,512	\$	77,279	\$	45,268			\$ 523,059

# FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF CASH FLOWS FOR THE YEAR ENDED SEPTEMBER 30, 2020 (WITH COMPARATIVE TOTALS FOR 2019)

		2020		2019
Cash flows from operating activities				
Change in net assets	\$	4,590	\$	87,174
Adjustments to reconcile change in net assets				
to net cash provided by operating activities:				
Depreciation		7,487		6,425
Loss on disposal of assets		394		-
Net realized and unrealized gain on investments		(102,932)	\$	(14,242)
Donated stock		(45,281)		-
Changes in operating assets and liabilities:				
(Increase) decrease in:				
Prepaid expense		(32,788)		(1,969)
Deposit - website		29,699		(29,699)
Deposits		(10,000)		(5,000)
(Decrease) increase in:				
Deferred revenue		(520)		520
Accounts payable and accrued expenses		(23,111)		65,517
Net cash (used in) operating activities		(172,462)		108,726
Cash flows used for investing activities				
Net proceeds from sale (purchase) of investments		2,599		-
Net transfer (to) from investment accounts		143,946		34,957
Reinvestment of dividends		(55,424)		(68,780)
Purchase of fixed assets		(29,699)		(5,267)
Net cash (used in) investing activities	******	61,422	-	(39,090)
Cash flows used for financing activities				
Proceeds from long-term debt		45,951		
Net cash (used in) financing activities		45,951	<b></b>	-
Net change in cash and cash equivalents	\$	(65,090)	\$	69,636
Cash and cash equivalents - beginning of the year		206,512		136,876
Cash and cash equivalents - end of year	\$	141,422	\$	206,512
222 2 242 242 2 2 2 3 3		- · -, ·	<u> </u>	
Supplemental Information:				
Cash paid for interest	\$	-	\$	-
Cash paid for income taxes	\$	-	\$	-

### 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 has been primarily based in the Philadelphia area since 1995, to allow better access to the Washington, DC area which has helped accomplish legislative advocacy including the National Ichthyosis Registry.

The Foundation prepares a quarterly newsletter, offers scholarships and support to the ichthyosis and related skin condition community, promotes research, and holds a national conference every other year to bring members together to attend lectures by leading physicians about ichthyosis as well as open discussion groups.

### 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.

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, where by the donor has stipulated the funds be maintained in perpetuity. At September 30, 2020, the Foundation had net assets with restrictions which are perpetual in nature in the amount of \$110,013. In total, the Foundation had \$868,196 in net assets with donor restrictions at September 30, 2020.

### **New 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 update addresses the complexity and understandability of ne asset classification, deficiencies in information about liquidity and availability of resources, and lack of

### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

### **New Accounting Pronouncement (Continued)**

consistency in the type of information provided about expenses and investment return. The Foundation adopted the new standard effective September 30, 2019 and had adjusted the presentation of these financial statements to comply with the standard.

### **Contributions and Grants**

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.

### **Measure of Operations**

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

### **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, 2020.

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

### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

### **Income Taxes (Continued)**

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.

### 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 and printers - 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, 2020:

	Amounts
Computer equipment and software	\$ 15,055
Website	58,168
	73,223
Less: accumulated depreciation and amortization	(34,112)
Property and equipment net of accumulated depreciation	
and amortization	\$ 39,111

Depreciation and amortization expense, relating to property and equipment, charged to operations was \$7,487 for the year ended September 30, 2020.

### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

### **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 services for the year ended September 30, 2020.

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 (Continued)**

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, 2020.

### **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, payroll service 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.

### **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, 2020, the amount of compensation for future absences is \$6,088. Accordingly, the liability has been recorded and included in accrued expenses.

### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

### **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, 2019, 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.

The following table shows Investments held by the Foundation as of September 30, 2020:

Mutual funds – fixed income	\$ 775,521
Exchange traded funds – fixed income	47,235
Mutual funds – equity	1,201,025
Exchange traded funds – equity	45,270
Total investments	\$ 2,069,051

The following table shows investment income including money market earnings for the year ended September 30, 2020:

Dividends and interest	\$ 60,113
Realized gains	35,820
Unrealized gains	67,112
Total investment income	\$ 163,045

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, they are netted with the unrealized gains and losses on the Statement of Activities. Investment earnings for year ending September 30, 2020 are included in net assets without donor restrictions.

### 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 Medical 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.

<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, 2020, none of the 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, 2020.

The following table shows the investments measured at fair value at September 30, 2020, grouped by the fair value hierarchy:

		Quoted Price	es in			
	Quoted prices in	Markets that		Significar		
	active markets for identical	not level 1		unobserva	ble	
5		similar assets		inputs	١	Total
Description	assets (Level 1)	(Level 2)		(Level 3)		Total
Mutual Funds and ETFs	\$ 2,069,051	\$	-	\$	-	\$ 2,069,051
Total at fair value	\$ 2,069,051	\$	-	\$	-	\$ 2,069,051

### 4. CONCENTRATIONS AND RISK

Financial instruments that potentially subject the Association 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, 2020, 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 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, 2020 was \$72,089 and \$2,069,051, respectively.

### 5. OPERATING LEASES

The Foundation's office space lease expired on June 30, 2020. The Foundation decided not to renew the lease and negotiated a four-month extension of the lease through October 31, 2020 at \$1,850 per month. Moving forward the Foundation's staff has been working remotely.

Rent expense included in the accompanying statement of functional expenses was \$24,804, including other charges and reimbursements.

### 6. MAJOR CONTRIBUTORS AND GRANTORS

The Foundation defines a significant contribution as greater than 10% of total support and revenue. During 2020, 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 \$600,000. In the event of unanticipated liquidity needs, the Foundation has the ability to scale-back and reduce non-essential support services.

### 7. LIQUIDITY AND AVAILABILITY OF RESOURCES (Continued)

The following represents the Foundation's financial assets as of September 30, 2020 that are allowable to meet cash needs for operating expenditures within one year:

Cash and cash equivalents	\$ 141,422
Investments	2,069,051
Total financial assets	2,210,473
Less:	
-accounts payable at September 30, 2020	(72,074)
-net assets with donor restrictions	(610,013)
Financial assets available to meet general expenditures	-
within one year	\$ 1,428,386

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

Changes in net assets with donor restrictions for the year ended September 30, 2020 are as follows:

	В	eginning				E	inding
·		Balance	Ad	ditions	Releases	В	alance
Temporarily restricted:							
Diya and Aliya's Friends (DAF)	\$	10,637	\$	1,000	\$ (5,771)	\$	5,865
Strategic Initiatives		126,141		5,418	(58,119)		73,440
Research		679,026		143,020	(143,169)		678,877
Total Temporarily restricted	\$	815,804	\$	149,438	\$ (207,059)	\$	758,183
Permanently restricted							
(Endowments):							
Membership assistance program		10,000		-	-		10,000
Research		100,013		-	 _		100,013
Total Permanently restricted	\$	110,013		_	-	\$	110,013
Total net assets with donor							
restrictions	\$	925,817	\$	149,438	\$ (207,059)	\$	868,196

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 three donor-restricted funds, Edna and Myron Curl Endowment, Milstone General Research Endowment, and the Jane Bukaty Membership Assistance Fund 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

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

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 assed 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. 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, and the Jane Bukaty Membership Assistance Fund 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 whose financial and reimbursement circumstances make obtaining adequate care and treatment difficult or impossible.

### 9. SUBSEQUENT EVENTS

The Foundation's management has performed subsequent events procedures through October 25, 2021, 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 except as follows.

Subsequent to September 30, 2020, due to the continuing global pandemic and public health emergency caused by the coronavirus (COVID 19) and the future economic uncertainty it brings, the Foundation applied for and received a second draw paycheck protection program (PPP) loan in the amount of \$49,999

### 9. SUBSEQUENT EVENTS (Continued)

to help supplement the Foundation's programs. It is expected this loan will be forgiven in the next fiscal year.

The Foundation moved its operations from an onsite corporate office model to fully remote model starting in November 2020.