



Pachyonychia Congenita Project

Fighting for a cure. Connecting & helping patients. Empowering research.

Financial Statements

And

Independent Auditor's Report

As of December 31, 2017

and for the year then ended

with summarized comparative information for December 31, 2016

Pachyonychia Congenita Fund

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INDEPENDENT AUDITOR'S REPORT

To the Board of Directors
Pachyonychia Congenita Fund
Holladay, Utah

Financial Statements

We have audited the accompanying financial statements of Pachyonychia Congenita Fund (a nonprofit organization), which comprise the statement of financial position as of December 31, 2017, 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 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.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit 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 financial statements are free of 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 auditor's 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 auditor considers 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 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 Pachyonychia Congenita Fund as of December 31, 2017, 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.

Report on Summarized Comparative Information

We have previously audited Pachyonychia Congenita Fund's 2016 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated May 17, 2017. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2016, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Shaw & Co., P.C.

May 18, 2018
Bountiful, Utah

Pachyonychia Congenita Fund
Statement of Financial Position
December 31, 2017
With Comparative Totals for December 31, 2016

	<u>12/31/2017</u>	<u>12/31/2016</u>
ASSETS		
Current assets		
Cash and cash equivalents	\$ 340,906	\$ 268,181
Prepays	10,195	-
Investments	<u>1,071,751</u>	<u>1,150,482</u>
Total current assets	<u>1,422,852</u>	<u>1,418,663</u>
Property and equipment, at cost	14,821	29,754
Less: accumulated depreciation and amortization	<u>(13,964)</u>	<u>(28,282)</u>
Net property and equipment	<u>857</u>	<u>1,472</u>
Total assets	<u>\$ 1,423,709</u>	<u>\$ 1,420,135</u>
LIABILITIES AND NET ASSETS		
Current liabilities		
Accounts payable	\$ 653	\$ 3,731
Accrued liabilities	<u>-</u>	<u>5,000</u>
Total current liabilities	<u>653</u>	<u>8,731</u>
Net assets		
Unrestricted	1,423,056	1,411,404
Temporarily restricted	-	-
Permanently restricted	<u>-</u>	<u>-</u>
Total net assets	<u>1,423,056</u>	<u>1,411,404</u>
Total liabilities and net assets	<u>\$ 1,423,709</u>	<u>\$ 1,420,135</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Activities
Year Ended December 31, 2017
With Comparative Totals for the Year Ended December 31, 2016

	December 31, 2017			12/31/2016	
	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>	<u>Total</u>
REVENUES AND SUPPORT					
Support					
Contributions	\$ 199,950	\$ -	\$ -	\$ 199,950	\$ 708,761
In-kind contributions	214,633	-	-	214,633	244,162
Grants	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>4,800</u>
Total support	<u>414,583</u>	<u>-</u>	<u>-</u>	<u>414,583</u>	<u>957,723</u>
Revenues					
Patient support fees	3,750	-	-	3,750	6,626
Other income	308	-	-	308	655
Interest and dividends	34,420	-	-	34,420	25,645
Unrealized gain on investments	75,763	-	-	75,763	58,737
Realized loss on investments	19,864	-	-	19,864	(10,876)
Special events	-	-	-	-	22,554
Less: cost of direct benefit to donors	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(12,515)</u>
Net special events	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>10,039</u>
Total revenues	<u>134,105</u>	<u>-</u>	<u>-</u>	<u>134,105</u>	<u>90,826</u>
Total revenues and support	<u>548,688</u>	<u>-</u>	<u>-</u>	<u>548,688</u>	<u>1,048,549</u>
EXPENSES					
Program services	475,645	-	-	475,645	605,806
Management and general	44,500	-	-	44,500	60,396
Fundraising	<u>16,891</u>	<u>-</u>	<u>-</u>	<u>16,891</u>	<u>22,526</u>
Total expenses	<u>537,036</u>	<u>-</u>	<u>-</u>	<u>537,036</u>	<u>688,728</u>
Change in net assets	11,652	-	-	11,652	359,821
Net assets, beginning of year	<u>1,411,404</u>	<u>-</u>	<u>-</u>	<u>1,411,404</u>	<u>1,051,583</u>
Net assets, end of year	<u>\$ 1,423,056</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 1,423,056</u>	<u>\$ 1,411,404</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund

Statement of Functional Expenses

Year Ended December 31, 2017

With Comparative Totals For The Year Ended December 31, 2016

	December 31, 2017				12/31/2016
	Program Services	Management and General	Fundraising	Total	Total
Salaries and wages	\$ 42,149	\$ 3,747	\$ 937	\$ 46,833	\$ -
Employee leasing	17,836	2,287	299	20,422	129,781
Employee benefits	3,307	294	74	3,675	-
Payroll taxes	3,224	287	72	3,583	-
	66,516	6,615	1,382	74,513	129,781
Total salaries and related expenses					
Professional services	235,498	21,014	4,083	260,595	311,736
Grants	61,936	-	-	61,936	66,200
Travel	42,747	40	15	42,802	60,194
Catering	27,145	-	-	27,145	19,090
Information technology	16,682	4,659	510	21,851	8,905
Occupancy	11,067	984	246	12,297	13,461
Office	7,373	953	1,752	10,078	14,091
Licenses and dues	-	35	8,678	8,713	8,717
Investment fees	-	8,712	-	8,712	6,500
Contract labor	5,357	-	-	5,357	53,451
Bank and merchant fees	214	328	213	755	1,265
Miscellaneous	56	561	-	617	3,509
Insurance	-	550	-	550	1,099
Meetings	500	-	-	500	2,181
	475,091	44,451	16,879	536,421	700,180
Total expenses before depreciation					
Depreciation	554	49	12	615	1,063
	475,645	44,500	16,891	537,036	701,243
Total functional expenses					
RECONCILIATION TO STATEMENT OF ACTIVITIES					
Less: cost of direct benefits to donors	-	-	-	-	(12,515)
	475,645	44,500	16,891	537,036	688,728
Total expenses					

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Cash Flows
Year Ended December 31, 2017
With Comparative Totals For the Year Ended December 31, 2016

	<u>12/31/2017</u>	<u>12/31/2016</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 11,652	\$ 359,821
Adjustments to reconcile change in net assets to net cash (used in) provided by operating activities		
Depreciation expense	615	1,063
Unrealized gain on investments	(75,763)	(58,737)
Changes in current assets and liabilities		
Accounts receivable, including promises to give	-	25,485
Prepays	(10,195)	-
Accounts payable	(3,079)	4,431
Accrued liabilities	(5,000)	33
	(81,770)	332,096
Net cash (used in) provided by operating activities		
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of investments	(78,220)	(476,083)
Proceeds from sale of investments	232,715	167,945
	154,495	(308,138)
Net cash provided by (used in) investing activities		
CASH FLOWS FROM FINANCING ACTIVITIES		
	-	-
Net change in cash and cash equivalents	72,725	23,958
Cash and cash equivalents, beginning of year	268,181	244,223
Cash and cash equivalents, end of year	\$ 340,906	\$ 268,181
SUPPLEMENTAL DISCLOSURE OF CASH FLOW INFORMATION		
Cash paid for interest	\$ -	\$ -
Cash paid for income taxes	\$ -	\$ -

See accompanying notes to financial statements.

Pachyonychia Congenita Fund

Notes to Financial Statements

December 31, 2017

1. ORGANIZATION HISTORY

Pachyonychia Congenita Fund (“The Organization”) was organized under the laws of the State of Utah in 2003 as a nonprofit corporation. The Organization’s mission is to fight for a cure for the Pachyonychia Congenita disease, connect and help patients, and empower research. The Organization supports a patient registry and coordinates research to develop and deliver therapeutics to persons afflicted with this disease. The Organization is supported by donations and grants from individuals, businesses, and private organizations.

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

The financial statements of the Organization have been prepared on the accrual basis. The Organization follows the provisions of Accounting Standards Codification (ASC) 958, *Not-for-Profit Entities*.

The significant accounting policies followed are described below to enhance the usefulness of the financial statements to the reader.

Date of Management’s Review

Subsequent events were evaluated through May 18, 2018, which is the date the financial statements were available to be issued. From their review, management has determined that there were no significant recognizable or unrecognizable subsequent events that were not properly disclosed.

Estimates in the Financial Statements

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities as of the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

Cash Equivalents

For purposes of the statement of cash flows, cash equivalents include time deposits, certificates of deposit, and all highly liquid debt instruments with original maturities of three months or less.

Concentrations of Credit Risks

The Organization maintains its cash in bank deposit accounts which, at times, may exceed federally insured limits. At December 31, 2017, cash in bank deposit accounts exceeded the FDIC insured limit of \$250,000 by \$84,718. The Organization has not experienced any losses in such accounts and believes it is not exposed to any significant credit risk on cash and cash equivalents since it seeks to mitigate this risk by depositing funds with high credit quality institutions.

Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable are carried at their estimated collectible amounts. The Organization’s accounts receivable are generally short-term in nature; thus accounts receivable do not bear interest.

Accounts receivable are periodically evaluated for collectibility based on past credit history with customers and their current financial condition. An allowance for doubtful accounts has not been established at December 31, 2017 because management believes that all accounts receivable will be fully collectible.

Promises to Give

Promises to give are recorded at their estimated fair value. Amounts due later than one year, if any, are recorded at the present value of estimated future cash flows. The Organization estimates the allowance based on analysis of specific donors, taking into consideration the age of past due pledges and an assessment of the donor's ability to pay. At December 31, 2017, management of the Organization considers all promises to be collectible; therefore, no allowance has been recorded.

Property and Equipment

Property and equipment are recorded at acquisition cost, or if donated, at the fair market value at the date donated. If donors stipulate how long the assets must be used, the contributions are recorded as restricted support. In the absence of such stipulations, contributions of property and equipment are recorded as unrestricted support. Depreciation expense is provided on a straight-line or double-declining-balance basis over the estimated useful lives of the respective assets or lease terms, which range from three to seven years. Depreciation expense for the year ended December 31, 2017 was \$615.

Impairment of Long-Lived Assets

The Organization evaluates its long-lived assets for any events or changes in circumstances which indicate that the carrying amounts of the assets may not be fully recoverable. The Organization evaluates the recoverability of long-lived assets by measuring the carrying amount of the assets against the estimated undiscounted future cash flows associated with them. When future undiscounted cash flows of certain long-lived asset are not sufficient to recover the carrying amounts of the assets, the assets are adjusted to their fair values.

Investments

The Organization has adopted the provisions of FASB ASC 958-320, *Investments—Debt and Equity Securities*. Investments in marketable securities with readily determinable fair values and all investments in debt securities are valued at their fair values in the statement of financial position. Unrealized gains and losses are included in the statement of activities.

Fair Value of Financial Instruments

The Organization has a number of financial instruments, none of which are held for trading purposes. The Organization estimates that the fair value of all financial instruments at December 31, 2017, does not differ materially from the aggregate carrying values of its financial instruments recorded in the accompanying statement of financial position.

Classes of Net Assets

Revenues and gains are classified based on the presence or absence of donor restrictions and reported in the following net asset categories:

- a) Unrestricted net assets represent the portion of net assets not subject to donor restrictions.
- b) Temporarily restricted net assets arise from contributions that are restricted by the donor for specific purposes or time periods.
- c) Permanently restricted net assets arise from contributions that are restricted by the donor in perpetuity.

All contributions are consisted available for unrestricted use, unless specifically restricted by the donors. All expenses are reported as changes in unrestricted net assets.

Contributions

Unconditional promises to give are recognized as contributions when received at the net present value of the amounts expected to be collected. Contributions are considered available for unrestricted use unless specifically restricted by the donor. Amounts received that are restricted by the donor for future periods or for specific purposes are reported as temporarily restricted or permanently restricted support that increases those net asset classes.

When a donor-imposed time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the accompanying statements of activities and changes in net assets as net assets released from restriction. Contributions with donor-imposed restrictions that are met in the current reporting period are reported as unrestricted contributions. Capital campaign contributions are considered temporarily restricted until the asset is placed into service.

In-Kind Contributions

In-kind contributions are recorded as support at their estimated fair market value at the date of gift. These contributions are reported as unrestricted support unless the donor has restricted the donation for a specific purpose. Assets donated with explicit restrictions regarding their use are reported as temporarily restricted support and reclassified to unrestricted net assets when placed in service. In-kind contributions received during the year ended December 31, 2017 consisted of the following:

Specialized services	
Physician and scientist	\$ 156,300
Executive director (see Note 5)	<u>58,333</u>
	<u>\$ 214,633</u>

In accordance with FASB ASC 958-605-25-16, *Contributed Services*, the Organization recognizes contributed services only if the services received (a) create or enhance nonfinancial assets or (b) require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation.

Program Service Revenue

Program service revenue consists of patient support meeting fees. Program service revenue is recognized when goods or services are provided.

Income Taxes

The Organization is exempt from federal income taxes under section 501(c)(3) of the Internal Revenue Code and therefore has made no provision for federal income taxes in the accompanying financial statements. In addition, the Organization has been determined by the Internal Revenue Service not to be a “private foundation” within the meaning of Section 509(a) of the Internal Revenue Code. There was no unrelated business income for the year ended December 31, 2017.

The Organization’s Forms 990, *Return of Organization Exempt from Income Tax*, for the years ending December 31, 2017, 2016, 2015, and 2014 are subject to examination by the IRS, generally for three years after they were filed. Generally accepted accounting principles require tax effects from an uncertain tax position to be recognized in the financial statements only if the position is more likely than not to be sustained if the position were to be challenged by a taxing authority. The assessment of the tax position is based solely on the technical merits of the position, without regard to the likelihood that the tax position may be challenged. If an uncertain tax position meets the more-likely-than-not threshold, the largest amount of tax benefit that is greater than 50% likely to be recognized upon ultimate settlement with the taxing authority is recorded. The Organization’s primary tax positions relate to its status as a not-for-profit entity exempt from income taxes and classification of activities related to its exempt purpose. Management has evaluated the tax positions reflected in the Organization’s tax filings and does not believe that any material uncertain tax positions exist.

Functional Allocation of Expenses

The cost of providing programs and other activities have been summarized on a functional basis in the statement of activities. The statement of functional expenses presents the natural classification detail of events by function. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

Reclassifications

Certain amounts in the summarized comparative information for 2016 have been reclassified to conform to the 2017 presentation.

3. FAIR VALUE MEASUREMENTS

In determining fair value, the Organization uses various valuation approaches within the fair value measurement framework. Fair value measurements are determined based on the assumptions that market participants would use in pricing an asset or liability. A hierarchy for inputs is used in measuring fair value that maximizes the use of observable inputs and minimizes the use of unobservable inputs by requiring that the most observable inputs be used when available. Levels within the hierarchy are based on the reliability of inputs as follows:

Level 1	Valuations based on unadjusted quoted prices for identical assets or liabilities in active markets
Level 2	Valuations based on quoted market prices for similar assets or liabilities or identical assets or liabilities in less active markets, such as dealer or broker markets
Level 3	Valuations derived from valuation techniques in which one or more significant inputs or significant value drivers are unobservable, such as pricing models, discounted cash flow models, and similar techniques not based on market, exchange, dealer, or broker-traded transactions.

The following tables sets forth by level, within the fair value hierarchy, the Organization's assets at fair value at December 31, 2017.

Assets at Fair Value at December 31, 2017

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual funds				
Money market	\$ 13,773	\$ -	\$ -	\$ 13,773
Foreign equity	24,464	-	-	24,464
U.S. equity	191,671	-	-	191,671
Corporate bond	175,093	-	-	175,093
Government bond	122,071	-	-	122,071
Real assets	45,015	-	-	45,015
Exchange-traded funds				
U.S. equity	-	139,912	-	139,912
Foreign equity	-	110,370	-	110,370
Government bond	-	218,316	-	218,316
Real assets	-	31,066	-	31,066
Totals	<u>\$ 572,087</u>	<u>\$ 499,664</u>	<u>\$ -</u>	<u>\$ 1,071,751</u>

Notes (continued)

There have been no changes in valuation techniques and related inputs. Certain of the Organization's investments classified as exchange-traded funds are recorded at net asset value in accordance with U.S. GAAP. Fair value represents the net asset value (NAV) of shares or units held by the Organization at year end. The financial statements of these investments are prepared in accordance with U.S. GAAP and are audited annually by independent auditors. As of December 31, 2017, the Organization had no unfunded commitments to invest in these funds. Redemptions, at NAV, of shares in these investments are immediate with one-day notice.

The composition of investment income on the Organization's investment portfolio for the year ended December 31, 2017 is as follows:

Interest and dividend income	\$ 34,354
Realized gains	19,864
Unrealized gains	75,638
Investment expenses	<u>(8,712)</u>
Investment income, net	<u>\$ 121,144</u>

4. PROPERTY AND EQUIPMENT

Property and equipment consisted of the following at December 31, 2017:

Computers and equipment	\$ 13,241
Furniture and fixtures	<u>1,580</u>
Property and equipment, at cost	14,821
Less: accumulated depreciation	<u>(13,964)</u>
Net property and equipment	<u>\$ 857</u>

Depreciation expense for the year ended December 31, 2017 was \$615.

5. RELATED PARTY TRANSACTIONS

During the year ended December 31, 2017, the Organization received significant contributions from related parties. The Organization's board chair contributed \$50,000 of support revenue. Foundation A, which is significantly influenced by the Organization's former executive director, contributed \$90,000 of support revenue. The Organization's board chair is related to the Organization's former executive director.

During the year ended December 31, 2017, the Organization purchased use of facilities and services from related parties. Company A, which is owned by the former executive director's sons, subleased occupancy space and provided employee leasing services to the Organization. Company A leases its building from the former executive director. During the year ended December 31, 2017, amounts paid to Company A totaled \$850 for rent and \$20,422 for employee leasing.

The Organization's executive director served on an uncompensated basis during the year ended December 31, 2017, donating in-kind contributions of professional services totaling \$58,333. In addition, the Organization's executive director also served as the executive director of Pachyonychia Congenita Project Europe, a Scottish Charitable Incorporated Organization. The Organization provided grants to Pachyonychia Congenita Project Europe during the year ended December 31, 2017 totaling \$60,031.

6. CONCENTRATIONS

During the year ended December 31, 2017, support received directly and indirectly from a related party represented 26% of the Organization's total revenue and support (see Note 5).

7. COMMITMENTS AND CONTINGENCIES

The Organization may be involved in certain claims arising from the ordinary course of operations and has purchased insurance policies to cover these risks.

8. PRIOR YEAR INFORMATION

The accompanying financial statements include certain 2016 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. The financial information for the year ended December 31, 2016 is presented for comparative purposes only. The notes presented herein contain information relating to December 31, 2017 only. Accordingly, such information should be read in conjunction with the Organization's financial statements for the year ended December 31, 2016 from which the summarized information was derived.