



Pachyonychia Congenita Project

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

Financial Statements

And

Independent Auditor's Report

As of December 31, 2018

and for the year then ended

with summarized comparative information for December 31, 2017

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, 2018, 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, 2018, 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.

Emphasis of Matter

As explained in Note 10 to the financial statements, in 2018, the Organization adopted Financial Accounting Standards Board's Accounting Standards Update (ASU) 2016-14, *Not-for-Profit Entities (Topic 958) – Presentation of Financial Statements of Not-for-Profit Entities* as of and for the year ended December 31, 2018. The requirements of the ASU have been applied retrospectively to all periods presented. Our opinion is not modified with respect to this matter.

Report on Summarized Comparative Information

We have previously audited Pachyonychia Congenita Fund's 2017 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated May 18, 2018. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2017, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Shaw & Co., P.C.

March 22, 2019
Bountiful, Utah

Pachyonychia Congenita Fund
Statement of Financial Position
December 31, 2018
With Comparative Totals for December 31, 2017

	<u>12/31/2018</u>	<u>12/31/2017</u>
ASSETS		
Current assets		
Cash and cash equivalents	\$ 780,001	\$ 340,906
Prepays	8,434	10,195
Investments	<u>1,014,324</u>	<u>1,071,751</u>
Total current assets	<u>1,802,759</u>	<u>1,422,852</u>
Property and equipment, at cost	17,314	14,821
Less: accumulated depreciation and amortization	<u>(14,390)</u>	<u>(13,964)</u>
Net property and equipment	<u>2,924</u>	<u>857</u>
Total assets	<u>\$ 1,805,683</u>	<u>\$ 1,423,709</u>
LIABILITIES AND NET ASSETS		
Current liabilities		
Accounts payable	<u>\$ 6,234</u>	<u>\$ 653</u>
Total current liabilities	<u>6,234</u>	<u>653</u>
Net assets		
Without donor restrictions	1,799,449	1,423,056
With donor restrictions	<u>-</u>	<u>-</u>
Total net assets	<u>1,799,449</u>	<u>1,423,056</u>
Total liabilities and net assets	<u>\$ 1,805,683</u>	<u>\$ 1,423,709</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Activities
Year Ended December 31, 2018
With Comparative Totals for the Year Ended December 31, 2017

	December 31, 2018			12/31/2017
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>	<u>Total</u>
REVENUES AND SUPPORT				
Support				
Contributions	\$ 800,723	\$ -	\$ 800,723	\$ 199,950
In-kind contributions	178,600	-	178,600	214,633
Total support	<u>979,323</u>	<u>-</u>	<u>979,323</u>	<u>414,583</u>
Revenues				
Patient support fees	154	-	154	3,750
Other income	556	-	556	308
Interest and dividends	39,054	-	39,054	34,420
Investment income	<u>(96,059)</u>	<u>-</u>	<u>(96,059)</u>	<u>86,915</u>
Total revenues	<u>(56,295)</u>	<u>-</u>	<u>(56,295)</u>	<u>125,393</u>
Total revenues and support	<u>923,028</u>	<u>-</u>	<u>923,028</u>	<u>539,976</u>
EXPENSES				
Program services	413,741	-	413,741	475,645
Management and general	43,390	-	43,390	35,788
Fundraising	<u>89,504</u>	<u>-</u>	<u>89,504</u>	<u>16,891</u>
Total expenses	<u>546,635</u>	<u>-</u>	<u>546,635</u>	<u>528,324</u>
Change in net assets	376,393	-	376,393	11,652
Net assets, beginning of year	<u>1,423,056</u>	<u>-</u>	<u>1,423,056</u>	<u>1,411,404</u>
Net assets, end of year	<u>\$ 1,799,449</u>	<u>\$ -</u>	<u>\$ 1,799,449</u>	<u>\$ 1,423,056</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Functional Expenses
Year Ended December 31, 2018
With Comparative Totals For The Year Ended December 31, 2017

	December 31, 2018				12/31/2017
	Program Services	Management and General	Fundraising	Total	Total
Salaries and wages	\$ 61,943	\$ 3,178	\$ 209	\$ 65,330	46,833
Employee leasing	-	-	-	-	20,422
Employee benefits	1,161	60	4	1,225	3,675
Payroll taxes	4,739	243	16	4,998	3,583
Total salaries and related expenses	67,843	3,481	229	71,553	74,513
Professional services	143,469	33,770	78,970	256,209	260,595
Grants	117,048	-	-	117,048	61,936
Travel	34,292	-	-	34,292	42,802
Information technology	17,953	2,227	358	20,538	21,851
Catering	13,646	-	-	13,646	27,145
Occupancy	11,451	1,627	508	13,586	12,297
Licenses and dues	504	44	8,450	8,998	8,713
Office	5,124	1,286	347	6,757	10,078
Meetings	2,000	-	-	2,000	500
Bank and merchant fees	7	194	641	842	755
Insurance	-	740	-	740	550
Contract labor	-	-	-	-	5,357
Miscellaneous	-	-	-	-	617
Total expenses before depreciation	413,337	43,369	89,503	546,209	527,709
Depreciation	404	21	1	426	615
Total functional expenses	\$ 413,741	\$ 43,390	\$ 89,504	\$ 546,635	\$ 528,324

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Cash Flows
Year Ended December 31, 2018
With Comparative Totals For the Year Ended December 31, 2017

	<u>12/31/2018</u>	<u>12/31/2017</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 376,393	\$ 11,652
Adjustments to reconcile change in net assets to net cash (used in) provided by operating activities		
Depreciation expense	426	615
Unrealized gain on investments	91,451	(75,763)
Changes in current assets and liabilities		
Prepays	1,761	(10,195)
Accounts payable	5,581	(3,079)
Accrued liabilities	<u>-</u>	<u>(5,000)</u>
Net cash (used in) provided by operating activities	<u>475,612</u>	<u>(81,770)</u>
 CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of property and equipment	(2,493)	-
Purchases of investments	(652,455)	(78,220)
Proceeds from sale of investments	<u>618,431</u>	<u>232,715</u>
Net cash provided by (used in) investing activities	<u>(36,517)</u>	<u>154,495</u>
 CASH FLOWS FROM FINANCING ACTIVITIES	<u>-</u>	<u>-</u>
 Net change in cash and cash equivalents	439,095	72,725
Cash and cash equivalents, beginning of year	<u>340,906</u>	<u>268,181</u>
Cash and cash equivalents, end of year	<u>\$ 780,001</u>	<u>\$ 340,906</u>
 SUPPLEMENTAL DISCLOSURE OF CASH FLOW INFORMATION		
Cash paid for interest	<u>\$ -</u>	<u>\$ -</u>
Cash paid for income taxes	<u>\$ -</u>	<u>\$ -</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund

Notes to Financial Statements

December 31, 2018

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. The Organization operates under the dba Pachyonychia Congenita Project.

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 March 22, 2019, 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 and Cash Equivalents

For purposes of the statement of cash flows, cash and 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, 2018, the Organization had bank deposits which exceeded the FDIC insured limit of \$250,000 by \$380,426. The Organization also holds cash and securities at investment firms. The investments held at those firms are insured through the Securities Investor Protection Corporation (SIPC) up to \$500,000 per institution. At December 31, 2018, the Organization had securities which exceeded the SIPC insured limit of \$500,000 by \$514,324. 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, 2018 because management believes that all accounts receivable will be fully collectible.

Promises to Give

Unconditional promises to give that are expected to be collected within one year are recorded at net realizable value. Unconditional promises to give expected to be collected in future years are initially recorded at fair value using present value techniques incorporating risk-adjusted discount rates designed to reflect the assumptions market participants would use in pricing the asset. In subsequent years, amortization of the discounts is included in contribution revenue in the statement of activities. The Organization determines the allowance for uncollectible promises to give based on historical experience, an assessment of economic conditions, and a review of subsequent collections. An allowance for uncollectible promises has not been established at December 31, 2018 because management believes that all promises to give will be fully collectible.

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, 2018 was \$426.

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.

Net Assets

Net assets, revenues, gains, and losses are classified based on the existence or absence of donor- or grantor-imposed restrictions. Accordingly, net assets and changes therein are classified and reported as follows:

- *Net Assets Without Donor Restrictions* – Net assets available for use in general operations and not subject to donor (or certain grantor) restrictions.
- *Net Assets With Donor Restrictions* – Net assets subject to donor- (or certain grantor-) imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity.

We report contributions restricted by donors as increases in net assets without donor restrictions if the restrictions expire (that is, when a stipulated time restriction ends or purpose restriction is accomplished) in the reporting period in which the revenue is recognized. All other donor-restricted contributions are reported as increases in net assets with donor restrictions, depending on the nature of the restrictions. 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. Gifts of long-lived assets and gifts of cash restricted for the acquisition of long-lived assets are considered net assets with donor restrictions until the asset is placed in service.

Contributions

Contributions are recognized as support when cash or an unconditional promise to give is received. Conditional promises to give are not recognized until the conditions on which they depend have been substantially met. Contributions are considered to be without donor restrictions unless restricted by the donor.

In-Kind Contributions

In-kind contributions are recorded as support at their estimated fair market value at the date of gift. These contributions are considered to be without donor restrictions unless restricted by the donor. Assets donated with donor-imposed restrictions regarding their use are considered net assets with donor restrictions until the asset is placed in service. In-kind contributions received during the year ended December 31, 2018 consisted of the following:

Specialized services	
Physician and scientist	\$ 37,800
Certified public accountant	1,800
Professional fundraising	39,000
Executive director (see Note 6)	<u>100,000</u>
	<u>\$ 178,600</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, 2018.

The Organization’s Forms 990, *Return of Organization Exempt from Income Tax*, for the years ending December 31, 2018, 2017, 2016, and 2015 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 supporting services activities have been summarized on a functional basis in the statement of activities. The statement of functional expenses presents the natural classification detail of expenses by function. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

The financial statements report certain categories of expenses that are attributed to more than one program or supporting function. Therefore, expenses require allocation on a reasonable basis that is consistently applied. The expenses that are allocated include salaries and wages, payroll taxes, employee benefits, professional services, occupancy, and depreciation, which are allocated on the basis of estimated time and effort.

Reclassifications

Certain amounts in the summarized comparative information for 2017 have been reclassified to conform to the 2018 presentation.

3. LIQUIDITY AND AVAILABILITY

Financial assets available for general expenditure, that is, without donor or other restrictions limiting their use, within one year of the balance sheet date consisted of the following:

Cash and cash equivalents	\$ 780,001
Investments	<u>1,014,324</u>
Total	<u>\$ 1,794,325</u>

None of the financial assets are subject to donor or other contractual restrictions that make them unavailable for general expenditure within one year of the balance sheet date. As part of our liquidity management plan, we invest cash in excess of daily requirements and maintain credit cards with an aggregate credit limit of \$26,000.

4. 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, 2018.

Assets at Fair Value at December 31, 2018

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual funds				
Money market	\$ 22,970	\$ -	\$ -	\$ 22,970
Foreign equity	77,193	-	-	77,193
U.S. equity	95,577	-	-	95,577
Corporate bond	61,724	-	-	61,724
Government bond	47,827	-	-	47,827
Foreign bond	30,558	-	-	30,558
Real assets	61,171	-	-	61,171
Exchange-traded funds				
U.S. equity	-	236,267	-	236,267
Foreign equity	-	38,697	-	38,697
Corporate bond	-	138,076	-	138,076
Government bond	-	174,949	-	174,949
Real assets	-	<u>29,315</u>	-	<u>29,315</u>
Totals	<u>\$ 397,020</u>	<u>\$ 617,304</u>	<u>\$ -</u>	<u>\$ 1,014,324</u>

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, 2018, 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.

Notes (continued)

The composition of investment income on the Organization's investment portfolio for the year ended December 31, 2018 is as follows:

Realized gains	\$ 3,184
Unrealized gains	(91,451)
Investment expenses	<u>(7,792)</u>
Investment income	<u>\$ (96,059)</u>

5. PROPERTY AND EQUIPMENT

Property and equipment consisted of the following at December 31, 2018:

Computers and equipment	\$ 15,734
Furniture and fixtures	<u>1,580</u>
Property and equipment, at cost	17,314
Less: accumulated depreciation	<u>(14,390)</u>
Net property and equipment	<u>\$ 2,924</u>

Depreciation expense for the year ended December 31, 2018 was \$426.

6. RELATED PARTY TRANSACTIONS

During the year ended December 31, 2018, the Organization received significant contributions from related parties. The Organization's executive director contributed \$98,355 of support revenue. The Organization's executive director served on an uncompensated basis during the year ended December 31, 2018, donating in-kind contributions of professional services totaling \$100,000. Corporation A, of which the executive director's spouse is an owner, contributed \$10,000 of support revenue. A former executive director, who is also related to the current executive director, contributed \$201,000 of support revenue. Foundation A, which is significantly influenced by the Organization's former executive director, contributed \$69,000 of support revenue.

7. CONCENTRATIONS

During the year ended December 31, 2018, support received directly and indirectly from related parties represented 41% of the Organization's total revenue and support (see Note 6).

8. COMMITMENTS AND CONTINGENCIES

The Organization leases office space under a noncancelable lease expiring October 2019 and requiring monthly payments of \$400. The Organization also leases office equipment under a noncancelable lease expiring October 2020 and requiring monthly payments of \$147. Future minimum payments required under these leases are as follows:

<u>Year Ended December 31,</u>	
2019	\$ 5,760
2020	1,466
Thereafter	<u>-</u>
Total	<u>\$ 7,226</u>

During the year ended December 31, 2018, rent expense related to office space totaled \$4,800 and is included in occupancy expense in the statement of functional expenses. During the year ended December 31, 2018, rent expense related to office equipment totaled \$1,189 and is included in office expense in the statement of functional expenses.

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

9. PRIOR YEAR INFORMATION

The accompanying financial statements include certain 2017 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, 2017 is presented for comparative purposes only. The notes presented herein contain information relating to December 31, 2018 only. Accordingly, such information should be read in conjunction with the Organization's financial statements for the year ended December 31, 2017 from which the summarized information was derived.

10. ADOPTION OF NEW ACCOUNTING PRONOUNCEMENT

For the year ended December 31, 2018, the Organization adopted the Financial Accounting Standards Board's Accounting Standards Update (ASU) 2016-14, *Not-for-Profit Entities (Topic 958) – Presentation of Financial Statements of Not-for-Profit Entities*. This guidance is intended to improve the net asset classification requirements and the information presented in the financial statements and notes about a not-for-profit entity's liquidity, financial performance, and cash flows. Main provisions of this guidance include:

- Presentation of two classes of net assets, versus the previously required three
- Recognition of capital gifts for construction as a net asset without donor restrictions when the associated long-lived asset is placed in service
- Recognition of underwater endowment funds as a reduction in net assets with donor restrictions and presentation of investment expenses as a reduction of investment income, versus the previously required gross presentation of investment expenses

The guidance also enhances disclosures for liquidity, board designated amounts, composition of net assets with donor restrictions, and expenses by both their natural and functional classification. The ASU has been applied retrospectively to all periods presented.