



Pachyonychia Congenita Project

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

Financial Statements

And

Independent Auditor's Report

As of December 31, 2019

and for the year then ended

with summarized comparative information for December 31, 2018

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, 2019, 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, 2019, 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 2018 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated March 22, 2019. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2018, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Bountiful Peak Advisors

April 30, 2020
Bountiful, Utah

Pachyonychia Congenita Fund
Statement of Financial Position
December 31, 2019
With Comparative Totals for December 31, 2018

	<u>12/31/2019</u>	<u>12/31/2018</u>
ASSETS		
Current assets		
Cash and cash equivalents	\$ 186,360	\$ 780,001
Accounts receivable, including promises to give	18,808	-
Prepays	20,864	8,434
Investments	<u>1,916,549</u>	<u>1,014,324</u>
Total current assets	<u>2,142,581</u>	<u>1,802,759</u>
Property and equipment	17,314	17,314
Accumulated depreciation	<u>(15,185)</u>	<u>(14,390)</u>
Net property and equipment	<u>2,129</u>	<u>2,924</u>
Total assets	<u>\$ 2,144,710</u>	<u>\$ 1,805,683</u>
LIABILITIES AND NET ASSETS		
Current liabilities		
Accounts payable	<u>\$ 6,687</u>	<u>\$ 6,234</u>
Total current liabilities	<u>6,687</u>	<u>6,234</u>
Net assets		
Without donor restrictions	\$ 2,138,023	\$ 1,799,449
With donor restrictions	<u>-</u>	<u>-</u>
Total net assets	<u>2,138,023</u>	<u>1,799,449</u>
Total liabilities and net assets	<u>\$ 2,144,710</u>	<u>\$ 1,805,683</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Activities
Year Ended December 31, 2019
With Comparative Totals for the Year Ended December 31, 2018

	December 31, 2019			12/31/2018
	Without Donor Restrictions	With Donor Restrictions	Total	Total
REVENUES AND SUPPORT				
Support				
Contributions	\$ 419,420	\$ -	\$ 419,420	\$ 800,723
In-kind contributions	<u>190,900</u>	<u>-</u>	<u>190,900</u>	<u>178,600</u>
Total support	<u>610,320</u>	<u>-</u>	<u>610,320</u>	<u>979,323</u>
Revenues				
Patient support fees	5,852	-	5,852	154
Other income	454	-	454	556
Interest and dividends	601	-	601	2,221
Net investment income	<u>202,225</u>	<u>-</u>	<u>202,225</u>	<u>(59,226)</u>
Total revenues	<u>209,132</u>	<u>-</u>	<u>209,132</u>	<u>(56,295)</u>
Total revenues and support	<u>819,452</u>	<u>-</u>	<u>819,452</u>	<u>923,028</u>
EXPENSES				
Program services	364,352	-	364,352	413,741
Management and general	40,676	-	40,676	43,390
Fundraising	<u>75,850</u>	<u>-</u>	<u>75,850</u>	<u>89,504</u>
Total expenses	<u>480,878</u>	<u>-</u>	<u>480,878</u>	<u>546,635</u>
Change in net assets	338,574	-	338,574	376,393
Net assets, beginning of year	<u>1,799,449</u>	<u>-</u>	<u>1,799,449</u>	<u>1,423,056</u>
Net assets, end of year	<u>\$ 2,138,023</u>	<u>\$ -</u>	<u>\$ 2,138,023</u>	<u>\$ 1,799,449</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Functional Expenses
Year Ended December 31, 2019
With Comparative Totals For The Year Ended December 31, 2018

	12/31/2019				12/31/2018
	Program Services	Management and General	Fundraising	Total	Total
Salaries and wages	\$ 65,969	\$ -	\$ 2,749	\$ 68,718	\$ 65,330
Employee benefits	-	-	-	-	1,225
Payroll taxes	5,047	-	210	5,257	4,998
Total salaries and related expenses	<u>71,016</u>	<u>-</u>	<u>2,959</u>	<u>73,975</u>	<u>71,553</u>
Professional services	141,711	35,882	61,995	239,588	256,209
Catering	74,284	37	-	74,321	13,646
Travel	26,467	-	-	26,467	34,292
Grants	14,500	-	-	14,500	117,048
Meetings	9,655	-	-	9,655	2,000
Licenses and dues	250	22	9,221	9,493	8,998
Office	8,010	677	69	8,756	6,757
Information technology	5,669	2,149	371	8,189	20,538
Contract labor	5,100	-	-	5,100	-
Occupancy	3,120	1,200	480	4,800	13,586
Insurance	3,470	589	-	4,059	740
Bank and merchant fees	337	20	723	1,080	842
Miscellaneous	-	100	-	100	-
Total expenses before depreciation	<u>363,589</u>	<u>40,676</u>	<u>75,818</u>	<u>480,083</u>	<u>546,209</u>
Depreciation	763	-	32	795	426
Total functional expenses	<u>\$ 364,352</u>	<u>\$ 40,676</u>	<u>\$ 75,850</u>	<u>\$ 480,878</u>	<u>\$ 546,635</u>

See accompanying notes to financial statements.

Pachyonychia Congenita Fund
Statement of Cash Flows
Year Ended December 31, 2019
With Comparative Totals For the Year Ended December 31, 2018

	<u>12/31/2019</u>	<u>12/31/2018</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 338,574	\$ 376,393
Items not requiring cash		
Depreciation expense	795	426
Noncash net investment income	(171,385)	91,451
Changes in		
Accounts receivable, including promises to give	(18,808)	-
Prepays	(12,429)	1,761
Accounts payable	<u>452</u>	<u>5,581</u>
Net cash provided by operating activities	<u>137,199</u>	<u>475,612</u>
 CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of property and equipment	-	(2,493)
Purchases of investments	(1,533,535)	(652,455)
Proceeds from sale of investments	<u>802,695</u>	<u>618,431</u>
Net cash used in investing activities	<u>(730,840)</u>	<u>(36,517)</u>
 Net change in cash and cash equivalents	(593,641)	439,095
Cash and cash equivalents, beginning of year	<u>\$ 780,001</u>	<u>\$ 340,906</u>
Cash and cash equivalents, end of year	<u>\$ 186,360</u>	<u>\$ 780,001</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, 2019

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. The Organization’s significant sources of revenue include contributions, in-kind contributions, and investment income.

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Basis of Accounting

The financial statements of the Organization have been prepared using the accrual method of accounting in accordance with accounting principles generally accepted in the United States of America (US GAAP).

Cash and Cash Equivalents

The Organization considers all cash and highly liquid financial instruments with original maturities of three months or less, and which are neither held for nor restricted by donors for long-term purposes, to be cash and cash equivalents. At December 31, 2019, the Organization did not hold cash equivalents.

Concentrations of Credit Risks

Financial instruments that potentially subject the Organization to concentrations of credit risk consist principally of cash and cash equivalents and investments. The Organization maintains its cash, cash equivalents, and investments in various bank accounts that, at times, may exceed federally insured limits. These assets have been placed with high credit quality financial institutions and the Organization has not experienced, nor does it anticipate, any losses with respect to such accounts.

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, 2019 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, 2019 because management believes that all promises to give will be fully collectible.

Property and Equipment

Property and equipment are recorded at cost at the date purchased or, if donated, at fair value at the date donated. Depreciation expense is calculated using the straight-line or double-declining-balance method over the estimated useful lives of the respective assets or lease terms, which are five years. Depreciation expense for the year ended December 31, 2019 was \$795. Management reviews the carrying value of property and equipment for impairment whenever events or circumstances indicate that the carrying value of an asset may not be recoverable from the estimated future cash flows expected to result from its use and eventual disposition. When considered impaired, an impairment loss is recognized to the extent carrying value exceeds the fair value of the asset.

Investments

Investments are initially recorded at cost, if purchased, or a fair value if donated. Thereafter, investments are reported at their value values in the statement of financial position. Net investment return is reported in the statement of activities and consists of interest and dividend income, realized and unrealized capital gains and losses, and investment management and custodial fees.

Fair Value Measurements

Fair value is defined as the price that would be received to sell an asset in the principal or most advantageous market for the asset in an orderly transaction between market participants on the measurement date. Fair value should be based on the assumptions market participants would use when pricing an asset. US GAAP establishes a fair value hierarchy that prioritizes investments based on those assumptions, with highest priority given to quoted prices in active markets and lowest priority to an entity's assumptions. The Organization groups assets at fair value in three levels, based on the markets in which the assets are traded and the reliability of the assumptions used to determine fair value. These levels are:

Level 1	Unadjusted quoted market prices for identical assets or liabilities in active markets as of the measurement date.
Level 2	Other observable inputs including quoted prices for similar assets in active or non-active markets, or other observable inputs for the asset.
Level 3	Unobservable inputs that cannot be corroborated by observable market data, such as pricing models, discounted cash flow models, and similar techniques.

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.

Revenue Recognition

Contributions- Contributions are recognized as support when cash, securities or other assets, or an unconditional promise to give is received. Conditional promises to give (those with a measurable performance or other barrier and a right of return) 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- Contributed goods, use of facilities, and services that either create or enhance nonfinancial assets or that require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation are recorded at fair value at the date of donation.

Program Service Revenue- Program service revenue consists of patient support meeting fees, which are recognized as revenue at the time patient support meetings are provided.

Income Taxes

The Organization has been recognized by the Internal Revenue Service (IRS) as exempt from federal income taxes under Section 501(c)(3), qualifying for the charitable contribution deduction under section 170(b)(1)(A)(vi), and has been determined not to be a private foundation under Section 509(a). The Organization is annually required to file a Return of Organization Exempt from Income Tax (Form 990) and is subject to income tax on net income that is derived from business activities that are unrelated to their exempt purposes. Management has determined that the Organization is not subject to unrelated business income tax. Management believes that the Organization has appropriate support for any tax positions taken in its annual filing and does not have any uncertain tax positions that are material to the financial statements. The Organization's Forms 990 are no longer subject to tax examination for years before 2016.

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.

Estimates in the Financial Statements

The preparation of financial statements in conformity with US GAAP requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Actual results could differ from those estimates.

Reclassifications

Certain amounts in the summarized comparative information for 2018 have been reclassified to conform to the 2019 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	\$ 186,360
Accounts receivable, including promises to give	18,808
Investments	<u>1,916,549</u>
Total	<u>\$ 2,121,717</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. The Organization invests cash in excess of daily requirements and maintains credit cards with an aggregate credit limit of \$26,000.

4. ACCOUNTS RECEIVABLE, INCLUDING PROMISES TO GIVE

At December 31, 2019, accounts receivable consisted of receivables from third party processors totaling \$18,808, which are expected to be collected within one year.

5. FAIR VALUE MEASUREMENTS

The following is a summary of investments at December 31, 2019.

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual funds				
Money market	\$ 22,564	\$ -	\$ -	\$ 22,564
Foreign equity	143,980	-	-	143,980
US equity	238,232	-	-	238,232
Corporate bond	859,605	-	-	859,605
Foreign bond	47,736	-	-	47,736
Real assets	80,098	-	-	80,098
Exchange-traded funds				
US equity	-	317,857	-	317,857
Foreign equity	-	63,318	-	63,318
Corporate bond	<u>-</u>	<u>143,159</u>	<u>-</u>	<u>143,159</u>
Totals	<u>\$ 1,392,215</u>	<u>\$ 524,334</u>	<u>\$ -</u>	<u>\$ 1,916,549</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 US 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 US GAAP and are audited annually by independent auditors. As of December 31, 2019, 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.

6. PROPERTY AND EQUIPMENT

Property and equipment consisted of the following at December 31, 2019:

Computers and equipment	\$ 15,734
Furniture and fixtures	<u>1,580</u>
Property and equipment	17,314
Accumulated depreciation	<u>(15,185)</u>
Net property and equipment	<u>\$ 2,129</u>

Depreciation expense for the year ended December 31, 2019 was \$795.

7. IN-KIND CONTRIBUTIONS

In-kind contributions received during the year ended December 31, 2019 consisted of the following:

Specialized services	
Physician and scientist	\$ 50,100
Certified public accountant	1,800
Professional fundraising	39,000
Executive director	<u>100,000</u>
 Total in-kind contributions	 <u>\$ 190,900</u>

8. RELATED PARTY TRANSACTIONS

During the year ended December 31, 2019, the Organization received significant contributions from related parties. The Organization’s executive director served on an uncompensated basis during the year ended December 31, 2019, contributing specialized services totaling \$100,000. A corporation owned by the executive director’s spouse contributed \$10,000 of support revenue during the year. A foundation significantly influenced by the Organization’s former executive director contributed \$200,000 of support revenue during the year.

9. CONCENTRATIONS

During the year ended December 31, 2019, support received directly and indirectly from related parties represented 38% of the Organization’s total revenue and support.

10. COMMITMENTS AND CONTINGENCIES

The Organization leases office space under a noncancelable lease expiring April 2021 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>	
2020	\$ 6,266
2021	1,600
Thereafter	<u>-</u>
 Total	 <u>\$ 7,866</u>

During the year ended December 31, 2019, 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, 2019, rent expense related to office equipment totaled \$1,767 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.

11. COMPARATIVE FINANCIAL INFORMATION

The accompanying financial statements include certain prior year summarized comparative information in total but not by net asset class or functional expense category. Such information does not include sufficient detail to constitute a presentation in conformity with US GAAP. Accordingly, such information should be read in conjunction with the Organization's financial statements for the year ended December 31, 2018 from which the summarized information was derived.

12. ADOPTION OF NEW ACCOUNTING PRONOUNCEMENTS

For the year ended December 31, 2019, the Organization adopted the Financial Accounting Standards Board's (FASB) Accounting Standards Update (ASU) 2014-09, *Revenue from Contracts with Customers (Topic 606)*. This guidance requires an entity to recognize revenue to depict the transfer of goods or services to customers in an amount that reflects the consideration to which an entity expects to be entitled in exchange for those goods or services. The guidance also requires expanded disclosures relating to the nature, amount, timing, and uncertainty of revenue and cash flows arising from contracts with customers, as well as other disclosures.

For the year ended December 31, 2019, the Organization adopted FASB's ASU 2015-08, *Not-for-Profit Entities: Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made (Topic 605)*. This clarifies that a contribution is conditional if the agreement includes both a barrier (or barriers) that must be overcome for the Organization to be entitled to the resources and a right of return for the assets transferred (or a right of release of the promisor's obligation to transfer assets).

Analysis of various provisions of these standards resulted in no significant changes in the way the Organization recognizes revenue, and therefore no changes to the previously issued audited financial statements were required on a retrospective basis. The presentation and disclosure of revenue have been enhanced in accordance with the standard.

13. SUBSEQUENT EVENTS

Subsequent events were evaluated through April 30, 2020, 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.

As a result of the spread of the COVID-19 coronavirus, economic uncertainties have arisen which are likely to negatively impact the Organization. Certain activities the Organization typically uses to accomplish its mission, such as travel and meetings, have been disrupted. While the disruption is currently expected to be temporary, there is considerable uncertainty around the duration. The related financial impact cannot be reasonably estimated at this time.

Subsequent to year end, the Organization was approved a \$15,600 uncollateralized loan under the Paycheck Protection Program created by the federal government as part of COVID-19 relief efforts. The loan accrues annual interest of 1% and payments are not required to begin for six months after the funding of the loan. The Organization is eligible for loan forgiveness upon meeting certain requirements.