

# **Pachyonychia Congenita Fund**

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**Financial Statements**

**And**

**Independent Auditor's Report**

**As of December 31, 2016**

**And for the year then ended**

# **Pachyonychia Congenita Fund**

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## INDEPENDENT AUDITOR'S REPORT

To the Board of Directors  
Pachyonychia Congenita Fund  
Salt Lake City, 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, 2016, 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, 2016, 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.

*Shaw & Co PC*

May 17, 2017  
Bountiful, Utah

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# Pachyonychia Congenita Fund

## Statement of Financial Position

December 31, 2016

### ASSETS

#### Current assets

Cash and cash equivalents	\$ 268,181
Investments	<u>1,150,482</u>

Total current assets	<u>1,418,663</u>
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#### Property and equipment, at cost

Property and equipment, at cost	29,754
Less: accumulated depreciation and amortization	<u>(28,282)</u>

Net property and equipment	<u>1,472</u>
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Total assets	<u>\$ 1,420,135</u>
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### LIABILITIES AND NET ASSETS

#### Current liabilities

Accounts payable	\$ 3,731
Accrued liabilities	<u>5,000</u>

Total current liabilities	<u>8,731</u>
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#### Net assets

Unrestricted	1,411,404
Temporarily restricted	-
Permanently restricted	<u>-</u>

Total net assets	<u>1,411,404</u>
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Total liabilities and net assets	<u>\$ 1,420,135</u>
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See accompanying notes to financial statements.

# Pachyonychia Congenita Fund

## Statement of Activities

Year Ended December 31, 2016

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
<b>REVENUES AND SUPPORT</b>				
Contributions	\$ 708,761	\$ -	\$ -	\$ 708,761
In-kind contributions	244,162	-	-	244,162
Special events	22,554	-	-	22,554
Less: cost of direct benefit to donors	<u>(12,515)</u>	<u>-</u>	<u>-</u>	<u>(12,515)</u>
Net special events	10,039	-	-	10,039
Patient support fees	6,626	-	-	6,626
Grants	4,800	-	-	4,800
Other income	655	-	-	655
Interest and dividends	25,645	-	-	25,645
Unrealized gain on investments	58,737	-	-	58,737
Realized loss on investments	<u>(10,876)</u>	<u>-</u>	<u>-</u>	<u>(10,876)</u>
Total revenue and support	<u>1,048,549</u>	<u>-</u>	<u>-</u>	<u>1,048,549</u>
<b>EXPENSES</b>				
Program services	605,806	-	-	605,806
Management and general	60,396	-	-	60,396
Fundraising	<u>22,526</u>	<u>-</u>	<u>-</u>	<u>22,526</u>
Total expenses	<u>688,728</u>	<u>-</u>	<u>-</u>	<u>688,728</u>
Change in net assets	359,821	-	-	359,821
Net assets, beginning of year	<u>1,051,583</u>	<u>-</u>	<u>-</u>	<u>1,051,583</u>
Net assets, end of year	<u>\$ 1,411,404</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 1,411,404</u>

See accompanying notes to financial statements.

# Pachyonychia Congenita Fund

## Statement of Functional Expenses

Year Ended December 31, 2016

	<u>Program Services</u>	<u>Management and General</u>	<u>Fundraising</u>	<u>Total</u>
Professional services	\$ 267,773	\$ 39,296	\$ 4,667	\$ 311,736
Employee leasing	112,736	10,095	6,950	129,781
Travel	75,190	40	-	75,230
Grants	66,200	-	-	66,200
Contract labor	52,703	512	236	53,451
Office	11,290	1,455	1,346	14,091
Occupancy	4,343	8,850	268	13,461
Information technology	8,683	110	112	8,905
Licenses and dues	775	151	7,791	8,717
Investment fees	-	6,500	-	6,500
Meals and entertainment	-	4,054	-	4,054
Miscellaneous	2,812	661	36	3,509
Meetings	2,181	-	-	2,181
Bank and merchant fees	197	604	464	1,265
Insurance	-	500	599	1,099
	<u>604,883</u>	<u>72,828</u>	<u>22,469</u>	<u>700,180</u>
Total expenses before depreciation				
Depreciation	<u>923</u>	<u>83</u>	<u>57</u>	<u>1,063</u>
Total functional expenses	<u>\$ 605,806</u>	<u>\$ 72,911</u>	<u>\$ 22,526</u>	<u>\$ 701,243</u>

### RECONCILIATION TO STATEMENT OF ACTIVITIES

Less: cost of direct benefits to donors	<u>-</u>	<u>(12,515)</u>	<u>-</u>	<u>(12,515)</u>
Total expenses	<u>\$ 605,806</u>	<u>\$ 60,396</u>	<u>\$ 22,526</u>	<u>\$ 688,728</u>

See accompanying notes to financial statements.

# Pachyonychia Congenita Fund

## Statement of Cash Flows Year Ended December 31, 2016

### CASH FLOWS FROM OPERATING ACTIVITIES

Change in net assets	\$ 359,821
Adjustments to reconcile change in net assets to net cash provided by operating activities	
Depreciation expense	1,063
Unrealized gain on investments	(58,737)
Changes in current assets and liabilities	
Accounts receivable, including promises to give	25,485
Accounts payable	4,431
Accrued payroll	<u>33</u>
Net cash provided by operating activities	<u>332,096</u>

### CASH FLOWS FROM INVESTING ACTIVITIES

Purchases of investments	(476,083)
Proceeds from sale of investments	<u>167,945</u>
Net cash used in investing activities	<u>(308,138)</u>

### CASH FLOWS FROM FINANCING ACTIVITIES

	<u>-</u>
Net change in cash and cash equivalents	23,958
Cash and cash equivalents, beginning of year	<u>244,223</u>
Cash and cash equivalents, end of year	<u>\$ 268,181</u>

### SUPPLEMENTAL DISCLOSURE OF CASH FLOW INFORMATION

Cash paid for interest	<u>\$ -</u>
Cash paid for income taxes	<u>\$ -</u>

See accompanying notes to financial statements.

# Pachyonychia Congenita Fund

## Notes to Financial Statements

December 31, 2016

### 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 17, 2017, 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, 2016, cash in bank deposit accounts exceeded the FDIC insured limit of \$250,000 by \$14,090. 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, 2016 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, 2016, 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, 2016 was \$1,063.

### 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, 2016, 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, 2016 consisted of the following:

Specialized services		
Physician and scientist	\$	166,650
Executive director (see Note 5)		66,667
Accounting		<u>10,845</u>
	\$	<u>244,162</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, 2016.

The Organization's Forms 990, *Return of Organization Exempt from Income Tax*, for the years ending December 31, 2016, 2015, 2014, and 2013 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.

### 3. FAIR VALUE MEASUREMENTS

The framework for measuring fair value provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (level 1) and the lowest priority to unobservable inputs (level 3). The three levels of the fair value hierarchy under FASB ASC 820 are described as follows:

Level 1	Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets that the Organization has the ability to access.
Level 2	Inputs to the valuation methodology include <ul style="list-style-type: none"> <li>• quoted prices for similar assets or liabilities in active markets;</li> <li>• quoted prices for identical or similar assets or liabilities in inactive markets;</li> <li>• inputs other than quoted prices that are observable for the asset or liability;</li> <li>• inputs that are derived principally from or corroborated by observable market data by correlation or other means</li> </ul> <p>If the asset or liability has a specified (contractual) term, the level 2 input must be observable for substantially the full term of the asset or liability.</p>
Level 3	Inputs to the valuation methodology are unobservable and significant to the fair value measurement.

The asset or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. Valuation techniques maximize the use of relevant observable inputs and minimize the use of unobservable inputs. Following is a description of the valuation methodologies used for assets measured at fair value. There have been no changes in the methodologies used at December 31, 2016.

*Mutual funds:* Valued at the closing price reported on the active market on which the individual securities are traded.

The following tables sets forth by level, within the fair value hierarchy, the Organization's assets at fair value at December 31, 2016.

#### **Assets at Fair Value at December 31, 2016**

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual funds	\$ 1,150,482	\$ -	\$ -	\$ 1,150,482
Totals	<u>\$ 1,150,482</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 1,150,482</u>

Notes (continued)

#### 4. PROPERTY AND EQUIPMENT

Property and equipment consisted of the following at December 31, 2016:

Computers and equipment	\$	28,174
Furniture and fixtures		<u>1,580</u>
Property and equipment, at cost		29,754
Less: accumulated depreciation		<u>(28,282)</u>
Net property and equipment	\$	<u><u>1,472</u></u>

Depreciation expense for the year ended December 31, 2016 was \$1,063.

#### 5. RELATED PARTY TRANSACTIONS

During the year ended December 31, 2016, the Organization's former executive director directly contributed \$167,424 of support revenue, including \$66,667 of contributed services. In addition, Foundation A, which is significantly influenced by the Organization's former executive director, contributed \$300,000 of support revenue.

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, 2016, amounts paid to Company A totaled \$129,781 for employee leasing. At December 31, 2016, accrued liabilities due to Company A totaled \$5,000 for rent.

#### 6. CONCENTRATIONS

During the year ended December 31, 2016, support received directly and indirectly from a related party represented 44% of the Organization's total revenue and support (see Note 5). Support received from Donor A represented 15% of the Organization's total revenue and support.

#### 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.