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# Pachyonychia Congenita Project

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

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**Financial Statements**

**And**

**Independent Auditor's Report**

**As of December 31, 2021**

**and for the year then ended**

**with summarized comparative information for December 31, 2020**

# **Pachyonychia Congenita Fund**

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## INDEPENDENT AUDITOR'S REPORT

To the Board of Directors  
Pachyonychia Congenita Fund  
Holladay, Utah

### *Opinion*

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, 2021, and the related statements of activities, functional expenses, and cash flows for the year then ended, and the related notes to the financial statements.

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, 2021, and the changes in net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

### *Basis for Opinion*

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Pachyonychia Congenita Fund and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

### *Responsibilities of Management for the Financial Statements*

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Pachyonychia Congenita Fund's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

### *Auditor's Responsibilities for the Audit of the Financial Statements*

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 Pachyonychia Congenita Fund's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about Pachyonychia Congenita Fund's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

***Report on Summarized Comparative Information***

We have previously audited Pachyonychia Congenita Fund's 2020 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated June 28, 2021. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2020, is consistent, in all material respects, with the audited financial statements from which it has been derived.

*Bountiful Peak Advisors*

Bountiful, Utah  
July 11, 2022

**Pachyonychia Congenita Fund**  
**Statement of Financial Position**  
**December 31, 2021**  
**With Comparative Totals for December 31, 2020**

	<u>12/31/2021</u>	<u>12/31/2020</u>
<b>ASSETS</b>		
Current assets		
Cash and cash equivalents	\$ 258,128	\$ 596,640
Prepays	2,965	4,584
Investments	<u>2,893,886</u>	<u>2,132,557</u>
Total current assets	<u>3,154,979</u>	<u>2,733,781</u>
Property and equipment	19,475	19,475
Accumulated depreciation	<u>(16,786)</u>	<u>(15,855)</u>
Net property and equipment	<u>2,689</u>	<u>3,620</u>
Total assets	<u>\$ 3,157,668</u>	<u>\$ 2,737,401</u>
<b>LIABILITIES AND NET ASSETS</b>		
Current liabilities		
Accounts payable	<u>\$ 2,485</u>	<u>\$ 1,971</u>
Total current liabilities	<u>2,485</u>	<u>1,971</u>
Net assets		
Without donor restrictions	3,155,183	2,735,430
With donor restrictions	<u>-</u>	<u>-</u>
Total net assets	<u>3,155,183</u>	<u>2,735,430</u>
Total liabilities and net assets	<u>\$ 3,157,668</u>	<u>\$ 2,737,401</u>

See accompanying notes to financial statements.

**Pachyonychia Congenita Fund**  
**Statement of Activities**  
**Year Ended December 31, 2021**  
**With Comparative Totals for the Year Ended December 31, 2020**

	<b>December 31, 2021</b>			12/31/2020
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>	<u>Total</u>
<b>REVENUES AND SUPPORT</b>				
Support				
Contributions	\$ 512,628	\$ -	\$ 512,628	\$ 541,574
In-kind contributions	203,006	-	203,006	176,200
Government grants	-	-	-	15,600
Total support	<u>715,634</u>	<u>-</u>	<u>715,634</u>	<u>733,374</u>
Revenues				
Other	18	-	18	218
Interest	98	-	98	206
Net investment income	<u>231,328</u>	<u>-</u>	<u>231,328</u>	<u>216,009</u>
Total revenues	<u>231,444</u>	<u>-</u>	<u>231,444</u>	<u>216,433</u>
Total revenues and support	<u>947,078</u>	<u>-</u>	<u>947,078</u>	<u>949,807</u>
<b>EXPENSES</b>				
Program services	407,577	-	407,577	247,162
Management and general	43,205	-	43,205	37,869
Fundraising	<u>76,543</u>	<u>-</u>	<u>76,543</u>	<u>67,369</u>
Total expenses	<u>527,325</u>	<u>-</u>	<u>527,325</u>	<u>352,400</u>
Change in net assets	419,753	-	419,753	597,407
Net assets, beginning of year	<u>2,735,430</u>	<u>-</u>	<u>2,735,430</u>	<u>2,138,023</u>
Net assets, end of year	<u>\$ 3,155,183</u>	<u>\$ -</u>	<u>\$ 3,155,183</u>	<u>\$ 2,735,430</u>

See accompanying notes to financial statements.

**Pachyonychia Congenita Fund**  
**Statement of Functional Expenses**  
**Year Ended December 31, 2021**  
**With Comparative Totals for the Year Ended December 31, 2020**

	<b>December 31, 2021</b>				12/31/2020
	Program Services	Management and General	Fundraising	Total	Total
Salaries and wages	\$ 67,402	\$ 1,483	\$ 3,315	\$ 72,200	\$ 68,718
Payroll taxes	5,156	113	254	5,523	5,257
Professional services	190,590	36,468	56,240	283,298	218,106
Grants	100,000	-	-	100,000	-
Information technology	29,899	1,278	5,638	36,815	32,005
Office	9,879	1,136	262	11,277	9,547
Licenses and dues	744	91	8,793	9,628	9,045
Occupancy	2,797	1,263	448	4,508	4,800
Bank and merchant fees	-	-	1,550	1,550	1,375
Depreciation	869	19	43	931	670
Miscellaneous	6	765	-	771	303
Insurance	-	589	-	589	589
Meetings	235	-	-	235	-
Travel	-	-	-	-	1,477
Catering	-	-	-	-	508
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
Total expenses	<u>\$ 407,577</u>	<u>\$ 43,205</u>	<u>\$ 76,543</u>	<u>\$ 527,325</u>	<u>\$ 352,400</u>

See accompanying notes to financial statements.

**Pachyonychia Congenita Fund**  
**Statement of Cash Flows**  
**Year Ended December 31, 2021**  
**With Comparative Totals for the Year Ended December 31, 2020**

	<u>12/31/2021</u>	<u>12/31/2020</u>
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Change in net assets	\$ 419,753	\$ 597,407
Items not requiring cash		
Depreciation	931	670
Donated investments	(200,000)	
Noncash net investment income	(76,512)	(157,250)
Changes in		
Accounts receivable, including promises to give	-	18,808
Prepays	1,619	16,280
Accounts payable	514	(4,716)
	<u>146,305</u>	<u>471,199</u>
Net cash provided by operating activities		
 <b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchases of property and equipment	-	(2,160)
Purchases of investments	(948,037)	(507,156)
Proceeds from sale of investments	463,220	448,397
	<u>(484,817)</u>	<u>(60,919)</u>
Net cash used in investing activities		
 Net change in cash and cash equivalents	(338,512)	410,280
Cash and cash equivalents, beginning of year	<u>596,640</u>	<u>186,360</u>
Cash and cash equivalents, end of year	<u>\$ 258,128</u>	<u>\$ 596,640</u>
 <b>SUPPLEMENTAL DISCLOSURE OF CASH FLOW INFORMATION</b>		
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, 2021

### 1. ORGANIZATION HISTORY AND NATURE OF ACTIVITIES

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 (U.S. 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, 2021, 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, 2021 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, 2021 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, 2021 was \$931. 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 at fair value if donated. Thereafter, investments are reported at fair value 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. U.S. 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.

The Organization reports 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 2018.

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 U.S. 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 2020 have been reclassified to conform to the 2021 presentation.

**3. LIQUIDITY AND AVAILABILITY**

The Organization regularly monitors liquidity required to meet annual operating needs and other commitments. The following table reflects the Organization's financial assets available as of December 31, 2021 for general expenditure over the next twelve months.

Cash and cash equivalents	\$ 258,128
Investments	<u>2,893,886</u>
Total	<u>\$ 3,152,014</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. FAIR VALUE MEASUREMENTS

The following is a summary of investments at December 31, 2021.

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Mutual funds				
Money market	\$ 104,424	\$ -	\$ -	\$ 104,424
Foreign equity	129,538	-	-	129,538
U.S. equity	1,001,626	-	-	1,001,626
Corporate bond	598,363	-	-	598,363
Foreign bond	147,064	-	-	147,064
Real assets	99,463	-	-	99,463
Exchange-traded funds				
U.S. equity	-	503,944	-	503,944
Foreign equity	-	138,799	-	138,799
Corporate bond	-	170,664	-	170,664
Totals	<u>\$ 2,080,478</u>	<u>\$ 813,407</u>	<u>\$ -</u>	<u>\$ 2,893,885</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, 2021, 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.

#### 5. PROPERTY AND EQUIPMENT

Property and equipment consisted of the following at December 31, 2021:

Computers and equipment	\$ 17,895
Furniture and fixtures	<u>1,580</u>
Property and equipment	19,475
Accumulated depreciation	<u>(16,786)</u>
Net property and equipment	<u>\$ 2,689</u>

Depreciation expense for the year ended December 31, 2021 was \$931.

**6. IN-KIND CONTRIBUTIONS**

In-kind contributions received during the year ended December 31, 2021 consisted of the following:

Specialized services	
Physician and scientist	\$ 65,200
Certified public accountant	1,800
Professional fundraising	36,000
Executive director	<u>100,006</u>
 Total in-kind contributions	 \$ <u>203,006</u>

**7. RELATED PARTY TRANSACTIONS**

During the year ended December 31, 2021, the Organization received significant contributions from related parties. The Organization’s executive director served on an uncompensated basis during the year ended December 31, 2021, contributing specialized services totaling \$100,006 and cash totaling \$82,825. 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 \$230,000 of support revenue during the year.

**8. CONCENTRATIONS**

During the year ended December 31, 2021, support received directly and indirectly from related parties represented 45% of the Organization’s total revenue and support.

**9. COMMITMENTS AND CONTINGENCIES**

The Organization leases office space under a noncancelable lease expiring September 2026 and requiring monthly payments of \$273, which escalate by 3% annually. The Organization also leases office equipment under a noncancelable lease expiring January 2025 and requiring monthly payments of \$144. Future minimum payments required under these leases are as follows:

<u>Year Ended December 31,</u>	
2022	\$ 5,053
2023	5,153
2024	5,256
2025	3,780
2026	2,795
Thereafter	<u>-</u>
 Total	 \$ <u>22,037</u>

During the year ended December 31, 2021, rent expense related to office space totaled \$4,359 and is included in occupancy expense in the statement of functional expenses. During the year ended December 31, 2021, rent expense related to office equipment totaled \$1,764 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.

## **10. 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 U.S. GAAP. Accordingly, such information should be read in conjunction with the Organization's financial statements for the year ended December 31, 2020 from which the summarized information was derived.

## **11. SUBSEQUENT EVENTS**

Subsequent events were evaluated through July 11, 2022, 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.