

**The White Family Foundation**  
**Grant Request #723-2022**  
The Payton Wright Foundation, Inc.  
March 1, 2022

<b>Date of grant proposal submission</b>	Tuesday, March 1, 2022
<b>Are you an IRS compliant 501(c)3 public charity/nonprofit?</b>	Yes
<b>Legal name of organization</b>	The Payton Wright Foundation, INC
<b>Address</b>	PO Box 110067 Bradenton, Florida 34211 United States
<b>Telephone</b>	941-867-0903
<b>Organization Director/ Title</b>	Margaret Lokey/Executive Director
<b>Contact Person/Title</b>	Meg Lokey/Executive Director
<b>Contact Person's Telephone</b>	727-460-0598
<b>Contact Person's Email</b>	<a href="mailto:mlokey@paytonwright.org">mlokey@paytonwright.org</a>
<b>Grant Request Amount</b>	\$20,000.00

**Please provide us with a brief description of your organization (no more than 500 words).**

All families face severe financial burdens when they have a child with brain cancer. Treatments are expensive and may only be available some distance from home. Parents have to take time off work to attend appointments and care for their child, and special equipment is often needed. The Payton Wright Foundation provides assistance by paying for gas cards, monthly rent, mortgage, and utility bills directly to the companies for these families. Often times bills must be paid the same day to prevent utilities from being shut off or an eviction.

**Grant Purpose (one paragraph)**

The Payton Wright Foundation is seeking a grant to expand our Financial Assistance Program within the Tampa Bay area with the objective of helping families keep their focus on their sick child. Families with a child with pediatric brain or Central Nervous System (CNS) cancer face extensive financial burdens from treatment and often miss extended periods of work, are forced to resign or take a leave of absence in order to provide around-the-clock care for their child after diagnosis and during treatment. The Payton Wright Foundation Financial Assistance Program provides financial assistance to families by paying monthly household bills for families whose income is decreased as a result of time spent caring for children. Past families who have received support through this program are from 21 different states and vary in age and race. The Payton Wright Foundation and the foundation pays those bills directly to the billing company. Types of assistance requested include utility bills, mortgage payments, car payments, childcare expenses, and sadly, funeral expenses. Funding is requested to support local families so the parents/caregivers of these sick children are able to keep their focus on their child for a longer period of time and be present with him/her during treatment or extended hospital stays without fear not being able to work to pay their household expenses. This will assist in the strategic planning goals of helping families for longer periods of time, which is beneficial for both the child’s health outcome and parents financial well-being during this critical time.

<b>Annual Project/Program Budget (if request is for a specific project)</b>	\$400,000.00
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<b>Annual Organization Budget</b>	\$625,000.00
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**T H E**  
**PAYTON WRIGHT**  
**F O U N D A T I O N**

## WHITE FAMILY FOUNDATION GRANT PROPOSAL

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## PROJECT ABSTRACT

The Payton Wright Foundation is seeking a grant to expand our Financial Assistance Program within the Tampa Bay area with the objective of helping families keep their focus on their sick child. Families with a child with pediatric brain or Central Nervous System (CNS) cancer face extensive financial burdens from treatment and often miss extended periods of work, are forced to resign or take a leave of absence in order to provide around-the-clock care for their child after diagnosis and during treatment. The Payton Wright Foundation Financial Assistance Program provides financial assistance to families by paying monthly household bills for families whose income is decreased as a result of time spent caring for children. Past families who have received support through this program are from 21 different states and vary in age and race.

The pediatric neuro-oncologists and social workers identify those families in need. They send the family's bills to The Payton Wright Foundation and the foundation pays those bills directly to the billing company. Types of assistance requested include utility bills, mortgage payments, car payments, childcare expenses, and sadly, funeral expenses. Funding in the amount of \$19,674 is requested to support 7 local families, at a rate of \$3,000 per family, so the parents/caregivers of these sick children are able to keep their focus on their child for a longer period of time and be present with him/her during treatment or extended hospital stays without fear not being able to work to pay their household expenses. This will assist in the strategic planning goals of helping families for longer periods of time, which is beneficial for both the child's health outcome and parents financial well-being during this critical time.

## STATEMENT OF NEED

More than 28,000 children (0-19 years of age) are estimated to be living with a brain tumor in the United States.<sup>2</sup> On average, 13 U.S. children are diagnosed with a brain tumor/cancer each day.<sup>3</sup> The average rate of survival for all primary pediatric malignant brain tumors is 74.1%.<sup>3</sup> Brain and Central Nervous System (CNS) tumors are the leading cause of cancer-related death among children, surpassing leukemia. Brain cancer had the highest per-patient initial cost of care for any cancer group, with an annualized mean net cost of care approaching \$150,000.<sup>4</sup> Brain cancer also had the highest annualized mean net costs for last-year-of-life care, relative to other cancers, at \$135,000-\$210,000 per patient. Brain tumor/cancer survivors often suffer from side effects of the treatments such as surgery, radiation, and chemotherapy resulting in lifelong physical learning and emotional challenges.

It is often necessary for parents to miss work or even take extended leaves of absence in order to provide around-the-clock care for their child after a pediatric brain cancer diagnosis. This may be due to frequent medical treatments and appointments. Children often require additional care while at home due to weakness or illness as a result of medical treatments such as chemotherapy. The financial strain of just one parent

Approximately one-third of caregivers reported a parent quitting or changing work as a result of their child's cancer diagnosis.<sup>5</sup> A cancer diagnosis in childhood can substantially affect the physical, psychosocial, and socioeconomic well-being of patients and their families. After 1 year from diagnosis, pediatric patients with cancer and their families may be increasingly vulnerable to financial stress related to unplanned hospitalizations and changes in parental employment.<sup>5</sup> After



the first year of diagnosis, a history of five or more unexpected hospitalizations—that is, admissions excluding planned chemotherapy visits—resulted in greater perceived financial stress.

Approximately 20% of families reported more than five unexpected hospitalizations. This increased to 35.7% of families 1 to 5 years from diagnosis.<sup>5</sup>

Treatment for cancer requires ongoing and regular inpatient and outpatient visits, often interrupting parents' work schedules. Families in which a caregiver had quit or changed work as a result of their child's cancer diagnosis experience a high financial burden. Mothers whose jobs were disrupted after their child's cancer diagnosis reported higher financial difficulty as a result of the cost of care.<sup>6</sup>

There are two major cost-related high points in the life course of a patient with cancer: first at diagnosis, and then at a later time when patients start experiencing late effects of treatment.<sup>7</sup> Patients with cancer and their families may need ongoing financial assistance well beyond the initial treatment phase to help them manage debt and access resources to cope with direct and indirect costs of cancer treatment. Furthermore, as a recent analysis demonstrated that cancer patients face a higher risk of personal bankruptcy than individuals without cancer,<sup>8</sup> unmanaged costs at the time of diagnosis could reduce patients' and families' financial capability later in life.

Support from friends, family, and employers, along with charitable financial assistance available at the time the child is diagnosed, may allow families to make accommodations that offset financial difficulties in the short-term. 84% Families who lose a child to cancer in the United States experienced work disruptions, and nearly 20% of families lost more than 40% of their annual income as a result of these work disruptions.<sup>9</sup> After the first year of cancer treatment, patients and families have further challenges of managing the financial costs of cancer in the face of job changes and unplanned hospitalizations. This could lead to severe financial repercussions such as bankruptcy,<sup>8</sup> refinancing of homes, loss of independence, and relationship breakdown, which may stress family roles and relationships<sup>10</sup> and have a long-term impact on household finances. As the financial costs of cancer accrue for families, efforts must be made to provide support throughout treatment and follow-up.

Financial, medical, and social support are needed for families on an ongoing basis, even after the end of primary therapy. Interventions to reduce and manage financial burden are most beneficial if initiated early in diagnosis and treatment before families become more vulnerable to the stress of indirect cancer costs.

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<sup>2</sup> Porter KR, McCarthy BJ, Freels S, Kim Y, Davis FG. "Prevalence Estimates for Primary Brain Tumors in the US by Age, Gender, Behavior, and Histology," *Neuro-Oncology*, 12(6): 520-527, 2010.

<sup>3</sup> *Central Brain Tumor Registry of the United States, 2013*

<sup>4</sup> de Blank, PM, et al. *Cancer Medicine*, 2015.

<sup>5</sup> Echo L. Warner, MPH, Anne C. Kirchoff, PhD, MPH, Gina E. Nam, Mark Fluchel, MD "Financial Burden of Pediatric Cancer for Patients and Their Families", *Journal of Oncology Practice*

<sup>6</sup> V Dussel, K Bona, JA Heath, et al: *Unmeasured costs of a child's death: Perceived financial burden, work disruptions, and economic coping strategies used by American and Australian families who lost children to cancer J Clin Oncol 29: 1007–1013, 2011*

<sup>7</sup> KR Yabroff, J Lund, D Kepka, et al: *Economic burden of cancer in the United States: Estimates, projections, and future research Cancer Epidemiol Biomarkers Prev 20: 2006–2014, 2011*

<sup>8</sup> S Ramsey, D Blough, A Kirchoff, et al: *Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis Health Aff (Millwood) 32: 1143–1152, 2013*

<sup>9</sup> V Dussel, K Bona, JA Heath, et al: *Unmeasured costs of a child's death: Perceived financial burden, work disruptions, and economic coping strategies used by American and Australian families who lost children to cancer J Clin Oncol 29: 1007–1013, 2011* Link, Google Scholar



<sup>10</sup> Z Amir, K Wilson, J Hennings , etal: *The meaning of cancer: Implications for family finances and consequent impact on lifestyle, activities, roles and relationships Psychooncology 21: 1167– 1174,2012*

## **PROGRAM DESCRIPTION**

The Payton Wright Foundation Financial Assistance Program provides financial assistance by paying monthly rent/mortgage, phone bills, utility bills, any daily bills for families, all over the nation, whose household income is decreased as a result of time spent caring for children. Qualifying families must have a child with pediatric brain/CNS cancer, be under the age of 19, and be actively receiving treatment or in palliative care. The pediatric neuro-oncologists and/or oncology social workers identify those families in need. It is a priority to The Payton Wright Foundation that these families are not burdened with a lengthy application process as they already have additional stressors and lack of time. The goal of this program is for the parents to be able to “Focus on their child,” so The Payton Wright Foundation uses approved social workers to pre-qualify families and identify those that need this program’s assistance.

Once a family in need is identified, the social workers send brief family demographic information along with copies of bills families need assistance with. The Payton Wright Foundation pays those bills directly to the billing company. Typical bills that are paid are mortgage, rent, phone, utility, insurance, daycare, funeral expenses, gas cards, car payments, and specialized medical equipment. The Foundation does not pay for medical, or hospital bills. Bills paid are only those associated with the household in which the child lives. No extended relatives or other caretakers may receive assistance.

There is no limit to the number of bills that are paid and there is no financial cap per family. Families may receive whatever assistance they need most for as long as they need it. Assisted families receive an average of \$2,000+ of assistance with an average of 2-3 bills paid. Financial assistance is only granted for 2 months after a child passes away, but is often needed the most during this time.

The Payton Wright Foundation, through its strategic plan, has a goal that instead of helping more families, to help families for a longer period of time, to ease their long-term financial burdens, and to help families keep their focus where it matters most: on their sick child.

## **GOALS & OBJECTIVES**

The goal of The Payton Wright Foundation Financial Assistance Program is to help parents of children with pediatric brain/spinal cord cancer by easing their financial burdens so that they can keep their focus where it matters most, on their child. Through strategic planning, The Payton Wright Foundation has set a goal to help 110 families in 2022 with an average value of program assistance of \$2,500. All family assistance is documented and accounted for with necessary documentation and demographic information reported for each family.

## **ORGANIZATION MISSION AND HISTORY**

The Payton Wright Foundation is a nonprofit, 501(c)(3) tax-exempt organization based in Bradenton, Florida. It was established in 2008 by Patrick and Holly Wright in memory of their daughter Payton



who lost her courageous battle with brain cancer in 2007. Patrick and Holly promised Payton they would never stop fighting, and thanks to their grit and perseverance and the generosity of many, the Payton Wright Foundation has helped hundreds of families across America that have children with brain cancer. The organization assists families by providing gas cards, paying for monthly housing costs and utility bills, and covering other critical needs while their child is in treatment. The Payton Wright Foundation does not pay for medical bills or expenses. Thanks to the Foundation's partnerships with dozens of children's hospitals in Florida and around the country, families with children with brain cancer are able to learn about the Payton Wright Foundation (often from hospital social workers) and initiate a request for assistance. Over \$1 Million in financial assistance to families has been provided since the organization's establishment.

The Payton Wright Foundation is governed by a Board of Directors comprised of family friends of the Wright's and business leaders. Holly Wright is the Interim Executive Director, provides administrative and programmatic leadership for the organization.



THE  
PAYTON WRIGHT  
FOUNDATION

INTERNAL REVENUE SERVICE  
P. O. BOX 2508  
CINCINNATI, OH 45201

DEPARTMENT OF THE TREASURY

Date: **SEP 25 2008**

THE PAYTON WRIGHT FOUNDATION INC  
C/O PATRICK WRIGHT  
6635 COOPERS HAWK CT  
BRADENTON, FL 34202

Employer Identification Number:  
33-1204054  
DLN:  
17053148013028  
Contact Person:  
TODD COLE ID# 75901  
Contact Telephone Number:  
(877) 829-5500  
Accounting Period Ending:  
December 31  
Public Charity Status:  
170(b)(1)(A)(vi)  
Form 990 Required:  
Yes  
Effective Date of Exemption:  
February 18, 2008  
Contribution Deductibility:  
Yes  
Addendum Applies:  
No

Dear Applicant:

We are pleased to inform you that upon review of your application for tax exempt status we have determined that you are exempt from Federal income tax under section 501(c)(3) of the Internal Revenue Code. Contributions to you are deductible under section 170 of the Code. You are also qualified to receive tax deductible bequests, devises, transfers or gifts under section 2055, 2106 or 2522 of the Code. Because this letter could help resolve any questions regarding your exempt status, you should keep it in your permanent records.

Organizations exempt under section 501(c)(3) of the Code are further classified as either public charities or private foundations. We determined that you are a public charity under the Code section(s) listed in the heading of this letter.

Please see enclosed Publication 4221-PC, Compliance Guide for 501(c)(3) Public Charities, for some helpful information about your responsibilities as an exempt organization.

Letter 947 (DO/CG)



## CURRENT BOARD OF DIRECTORS

**Patrick Wright** (Chair) – Co-Founder of The Payton Wright Foundation, Patrick and his wife lost their 5-year-old daughter to brain cancer in 2007. Through this experience, they learned firsthand how families can suffer financial burdens beyond those of the medical treatments by choosing to spend the last moments of their daughter’s life with her. Patrick works in the insurance industry and brings leadership, fundraising and local awareness to the board of directors.

**Cole Collins** (Secretary) – Real estate agent and business owner, Cole brings PR, business management and organizational skills to the foundation. In addition, he is one of the two millennials on the board.

**Kym Berceau** - Experienced benefits consultant with strong information technology professional skilled in HR Consulting, Coaching, Sales, Sales Operations, and Training.

**Steve Cavanaugh** – Broker/Owner of a real estate company and vacation rental company with experience in fundraising, business management, marketing and philanthropy.

**Jack Collins** – Large business owner and longtime Sarasota resident, Jack has skills in management, event fundraising and human resources.

**Eric Fleming** – Attorney at law, with knowledge in nonprofit management, fundraising and governance and provides endless assistance with policy writing and governance structure to the organization. Eric serves as president to a local charity as well.

**Jordan Fleming** – Pharmaceutical Sales Representative with expertise in health care and fundraising. Jordan co-chairs one of our major fundraising events.

**Keith Mercier** - President of Insurance Risk Consultant business with extensive knowledge of nonprofit governance and foundation management. Keith serves as president of another local non-profit.

**Dr. Robert Morelli** – Dr. Morelli is the doctor that originally diagnosed Payton in 2006. With extensive knowledge of hospitals, social workers and health care, “Doc” brings to the foundation a unique perspective for how these families struggle and how we can best work with different aspects of hospitals to be most effective.

**Brian Porter** – Operations & business development manager for national company. Brian has past experience working for a non-profit and fundraising and has chaired the organization’s major fundraiser for the past 10 years.



**Jay Riley** – Director of Business Outreach and Community Engagement for the University of South Florida. Jay has vast experience working with local businesses and non-profits. Jay has played major roles in fundraising bringing local businesses together to address community needs.

**Robert Sket** – CEO of national organization with over 20 years of dedicated leadership and development in various industries through extensive application of financial analysis, strategic planning, and expansion into new markets. Robert brings extensive accounting and nonprofit board experience to PWF’s board of directors.

## **STAFF**

**Holly Wright**, (Interim Executive Director) - Co-Founder of The Payton Wright Foundation, Holly and her husband lost their 5-year-old daughter to brain cancer in 2007. Through this experience, they learned firsthand how families can suffer financial burdens beyond those of the medical treatments by choosing to spend the last moments of their daughter’s life with her. Holly ran the organization as the only employee for 10 years before hiring the current Executive Director to take over. She now works as an occupational therapist but continues to provide organizational support to the foundation.



## Payton Wright Foundation Financial Assistance Program 2022 Budget

### PROPOSED INCOME

	Revenue Source	Description	Amount	Percentage of Total
1	<b>Direct Public Support (Donations)</b>	Includes individual and corporate gifts	\$190,500	65%
2	<b>Grants</b>		\$50,000	17%
3	<b>Special Events Income</b>	Revenues from Annual Golf Tournament,	\$54,000	18%
<b>Total Proposed Revenue</b>			<b>\$ 294,500</b>	

### PROPOSED EXPENSES

	Expense	Description	Amount	Percentage of Total
1	<b>Direct Support</b>	Bills paid directly for families	\$264,000	90%
2	<b>Wages</b>	Wages & Taxes for support staff	\$30,000	10%
3	<b>Postage</b>	Postage costs for mailing checks to pay bills	\$300	0%
4	<b>Printing</b>	Envelopes to mail bills	\$200	0%
<b>Total Proposal Expenses</b>			<b>\$ 294,500</b>	