

F.M. KIRBY FOUNDATION SOLICITATION EVALUATION FORM

DATE: April 4, 2023

REQUEST DATE: March 8, 2023

Last grant acknowledgment: Yes

Program Area: Health

APPLICANT:

The Leukemia & Lymphoma Society, Inc.

New Jersey Chapter

Suite 301

14 Commerce Drive

Cranford, NJ 07016

CONTACT: Ms. Jana Boyer, Executive Director, New Jersey Chapter

PHONE: 908-956-6600

PAYEE OTHER THAN ADDRESSEE:

AMOUNT REQUESTED: \$125,000 **NATURE OF REQUEST:** Toward the Dare to Dream Project

GRANT HISTORY

SUPPORT: 1979-2022

OF GRANTS: 35

TOTAL DOLLARS: \$3,315,000

LAST GRANT DATE: 05/02/2022

LAST GRANT AMOUNT: \$100,000

FYE DATE: 6/30/2022

AFS DATE: 10/25/2022

2022	\$100,000.00	05/02/2022	Toward the LLS Children's Initiative
2021	\$100,000.00	05/03/2021	Toward the LLS Children's Initiative
2020	\$100,000.00	04/29/2020	Toward the LLS Children's Initiative
2019	\$100,000.00	04/15/2019	Toward the LLS Children's Initiative
2018	\$125,000.00	04/23/2018	For: Ongoing Acute Myeloid Leukemia research within the Beat AML Initiative

DLK COMMENTS: This year's request covers much of what was discussed in the call that Emily and I had with Gwen Nichols, EVP, Chief Medical Officer, Jana Boyer and Matt Mastrianni, Advancement Director in February 2023. Dr. Nichols shared some somber statistics. 40% of pediatric cancers are blood cancers; approximately 80% of childhood cancer survivors develop chronic health issues from treatment; and only 5% of cancer drugs approved in the past 40 years have been approved for first-time use in children.

The Dare to Dream Project is billed as the "bigger, bolder, next phase of LLS Children's Initiative" and aims to change the paradigm of treatment and care for pediatric blood cancer patients. Pediatric cancers are different and should be treated differently. LLS aims to raise \$175 million over five years to support research and the development of treatments for pediatric blood cancers. There are

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three pillars to the Dare to Dream Project: 1) increase research grants and lead a master trial, 2) expand support for children and families, and 3) drive policy to break down barriers to treatment and care.

With regard to research, LLS currently has 34 grants devoted to childhood blood cancer, comprising an investment of more than \$26 million. Highlights of newly funded projects include:

- Dr. Terry Fry, University of Colorado, is engineering a chimeric antigen receptor (CAR) T cell that simultaneously targets two different proteins on the Acute Myeloid Leukemia (AML) cell, making the treatment more potent and widely effective.
- Dr. Carl June, University of Pennsylvania, is developing CAR T-cell therapy for various blood cancers, including Acute Lymphoblastic Leukemia (ALL) and AML. The therapy targets a protein called CD38 found on AML cancer cells which plays a role in cancer's ability to evade the immune system.

The LLS Pediatric Master Clinical Trial for Acute Leukemia (PedAL) continues to gain momentum. The goal of running the trial at 200 sites globally has been doubled to bring PedAL to more than 400 sites worldwide! Dr. Nichols stated that pediatric clinical trials are a logistical nightmare and LLS is setting out to establish an infrastructure to improve the process. They have 145 pediatric sites in North America identified to run screening trials. The screening trial is for children who have had a relapse of AML or a subtype of ALL. So far, 73 children have been screened at the sites. Additionally, the screening is about to open in Australia and New Zealand.

The first PedAL drug trial (utilizing Venetoclax) is being tested in children with Abbvie fully funding the trial while LLS is responsible for building out the infrastructure (paying doctors while writing the trials, providing patient and family support, funding biostatisticians for data collection and analysis, etc.) It opened in the U.S. and Europe in 2022. As of February 28, 2023, the study has opened 22 centers in the U.S. and Canada, two in Europe, and has recruited six patients. Morristown Medical Center is one of the 22 centers that have opened this trial thus far. Three additional drug trials are being finalized and it's anticipated one will open in the U.S. this spring, with the other two opening domestically and globally later this year.

LLS has had to work through some data sharing issues as the Children's Oncology Group (COG) database couldn't merge with European databases due to GDPR (General Data Protection Regulation) standards. This resulted in them developing an intermediary that is compliant with those standards. LLS continues to work to integrate and align historical and new data in a cloud-based repository for researchers. Currently, data from the Japan Children's Cancer Group (JCCG), COG and the European consortium Berlin-Frankfurt-Munster (BFM) is being processed for import into the Data Commons.

LLS offers many types of support for families facing a blood cancer diagnosis. There is one-on-one support, including highly trained oncology social workers and nurses who provide personalized support, registered dietitians with expertise in oncology nutrition, and clinical trial nurse navigators who help patients find and enroll in a clinical trial based upon detailed, individualized assessments. They also have a library of resources including webcasts, videos, downloadable material, podcasts, mobile apps, and online chats. We were excited to learn of the LLS Scholarships for Blood Cancer Survivors to help them keep their educational and career goals on track. The first class of 100

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recipients will finish the inaugural year this spring, and the second round of applications is currently being reviewed. The scholarships provide up to \$7,500 to support tuition expenses for students attending two-year, four-year, or vocational programs and can be renewed every year while the student remains eligible.

The final pillar addresses policy and advocacy. LLS co-chairs the Alliance for Childhood Cancer's Policy Committee. It played a significant role in the Childhood Cancer Survivorship, Treatment, Access & Research (STAR) Act and the Research to Accelerate Cures and Equity (RACE) for Children Act. The [STAR Act](#) was set to expire at the end of 2023. LLS was actively speaking with lawmakers in 2022 and the act was extended for another five years (President Biden signed the STAR Act on January 5, 2023). Click the link for more details on the STAR Act. The RACE for Children Act was modified in June 2022 to limit waivers of pediatric assessments for medications that target a molecule germane to a pediatric cancer for which there is a need for additional treatment options. Click [here](#) to learn more. Senators Chuck Grassley and Michael Bennet and Assistant Speaker Katherine Clark introduced a bipartisan, bicameral bill called the Accelerating Kids' Access to Care Act which would ensure that coordination can happen across state lines by clarifying the process by which state Medicaid programs can cover this care regardless of where the child lives and where their care is received. This would allow children with complex medical needs greater, more expeditious access to providers who can best meet their needs.

On March 30, 2023, the U.S. District Court issued a ruling that jeopardizes access to proven, life-saving preventive care. Judge Reed O'Connor (TX) ruled that the U.S. Preventive Services Task Force (USPSTF) coverage requirement that Affordable Care Act (ACA)-compliant health insurers must cover USPSTF-recommended services without cost sharing must be vacated and cannot be enforced by the U.S. Department of Health and Human Services. The remedy is a sweeping decision that threatens access to lifesaving cancer screenings and other preventive screenings and services for millions of people across the country. LLS and 15 other patient organizations, including the American Cancer Society, filed an amicus brief in November 2022 urging the U.S. District Court to preserve the requirement and included scientific data on how preventive care saves lives and is cost-effective. The group issued a statement regarding the recent ruling. In summary, since the ACA was implemented in 2010 and these screenings and services were required to be covered with no cost-sharing, preventive and regular care rates have increased. Taking that away from the more than 150 million people that the US Dept. of Health and Human Services has found have benefitted from the ACA's coverage will negatively impact health outcomes. The confusion and uncertainty around coverage will no doubt be a deterrent to early and effective life-saving measures.

This ruling highlights the importance of private philanthropy in funding research and support for families. Everyone should have access to the latest clinical trials and treatments, as well as basic screening. Philanthropy can play a large role in ensuring equitable access. I recommend \$125K for the Dare to Dream Project.

Financial analysis attached.

JJK COMMENTS: I would add to the above that the District Court ruling is also evidence of the importance of LLS's (and other medical organizations') role in advising legislators and shaping

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policy. It does not take a great deal of imagination to conjure how devastating a diagnosis of childhood leukemia would be for a family. One shudders to think that the recent ruling might reduce the number of early interventions and make those diagnoses far more grim.

LLS continues to exhibit fine stewardship. Dr. Nichols is an effective communicator of the project and of the importance of FMKF support. I am glad ECP has had a chance to meet with the LLS team.

The disinclination of big pharma to invest money in childhood leukemia and lymphoma – coupled with the lack of incentives for worldwide data sharing and collaboration – make the Dare to Dream project a compelling case for private philanthropy. I also recommend \$125K for the Dare to Dream Project.

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FM KIRBY FOUNDATION			
Financial Statement Analysis			
Grantee Name:	The Leukemia & Lymphoma Society	Date:	3/30/2023
Prepared By:	DLK		
Grant Request Amt.	\$ 125,000	Type of Financial Report Submitted	Audit - National
Budgeted Amt.	\$ 125,000	Period Covered in Financial Report	6/30/2022
Audit Firm	KPMG	Date of Report Issuance	10/25/2022
Opinion	Present fairly		
Basis of Acctg.	GAAP		
Current Ratio (Liquidity Ratio/Working Capital Ratio)	3.99	Amount of Unrestricted Net Assets (Operating Reserve)	\$ 316,414
	Liquidity (Note 5)/CL		(in thousands)
Note: A current ratio measures an organization's ability to pay short-term and long-term obligations. The higher the ratio, the more capable the organization is of paying its obligations. A ratio under 1 indicates that the organization's liabilities are greater than its assets.			
Allocation of Functional Expenses	6/30/2022	%	Must Read Financial Statement Notes
A. Program Service Expenses	\$ 433,741	81%	Ideally program expenses should be
B. Management and General	\$ 54,039	10%	at least 70% of total budget.
C. Fundraising	\$ 46,457	9%	
D. Total Expenses	\$ 534,237	100%	
	(in thousands)		
Comments/ Notes:			
<p>FY23 Budget: The National budget for FY23 is forecasting a \$19.7M deficit vs a deficit of \$90.4M for FY22. Total operating revenues are projected to decline by \$36.0M (8%), with co-pay contributions down \$24.3M (19%) and TAP contract revenues budgeted at \$0 (vs \$9.7M for FY22). Total operating expenses are budgeted to decrease \$106.7M (20%), with patient and community services (co-pay assistance) down \$150.9M (50%), and research up \$30.1M (32%).</p> <p>The FY23 budget for LLS NJ is forecasting a \$6.6M surplus vs a \$6.8M surplus for FY22. Revenues are decreasing by \$69.6K (1%), while expenses are growing by \$130.6K (6%) with payroll/benefits up \$189.6K (11%), travel/meetings up \$19.4K, postage/shipping up \$35.3K (102%) and rent down \$49.5K (247%).</p> <p>FY22 Audit: (LLS National) LLS had an operating deficit of \$90.3M vs a surplus of \$112.3M for FY21. Total net assets declined by \$142.8M vs an increase of \$151.5M in FY21 due to a decrease in the fair value of investments, along with the operating loss. Total operating revenues were down \$40.1M (8%), an increase in contributions (\$14.3M/6%) being offset by a decrease in co-pay contributions (\$55.2M/30%). Total program services expense grew \$159.0M (58%), primarily in patient and community service (up \$132.3M/77%). Patient and community service is where co-pay assistance resides. Supporting services expense increased by \$3.6M (4%). LLS had investments totaling \$652.9M as of June 30, 2022, of which \$7.8M were endowment-related. There were no red flags as a result of my review.</p>			

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DISPOSITION:

- Declination
- Hold for review on/about:
- Approval for: **\$125,000**
- Hold for Board Review
- Insert Information: **Toward support of the Dare to Dream Project**
- Other:

Initials: JK

Date: 04/12/2023

Check #

Date: