

F.M. KIRBY FOUNDATION SOLICITATION EVALUATION FORM

DATE: April 5, 2022

REQUEST DATE: March 10, 2022

Last grant acknowledgement: Yes

Program Area: Health

APPLICANT:

The Leukemia & Lymphoma Society, Inc.
New Jersey Chapter
Suite 301
14 Commerce Drive
Cranford, NJ 07016

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

PHONE: 908-956-6602

PAYEE OTHER THAN ADDRESSEE:

AMOUNT REQUESTED: \$125,000 **NATURE OF REQUEST:** Toward LLS Children’s Initiative

GRANT HISTORY

LAST GRANT DATE: 5/3/2021

LAST GRANT AMOUNT: \$100,000

FYE DATE: 6/30/2021

AFS DATE: 10/25/2021

2017	\$125,000	4/28/2017	For: Ongoing Acute Myeloid Leukemia research within the Beat AML Initiative
2018	\$125,000	4/23/2018	For: Ongoing Acute Myeloid Leukemia research within the Beat AML Initiative
2019	\$100,000	4/15/2019	Toward the LLS Children’s Initiative
2020	\$100,000	4/29/2020	Toward the LLS Children’s Initiative
2021	\$100,000	5/3/2021	Toward the LLS Children's Initiative

DLK COMMENTS: The request largely reflects the conversation that Justin and I had during our call with Dr. Gwen Nichols, Chief Medical Officer, and Jana Boyer, Executive Director of the NJ Chapter, in February. The LLS PedAL trial, which the Foundation has been funding since 2019, focuses on children with relapsed Acute Myelogenous Leukemia, a type of cancer of the blood and bone marrow, and other high-risk pediatric leukemias. The screening trial and first drug trial arm were officially approved by the U.S. Food & Drug Administration in January 2022 with plans for up to seven drug trial arms to follow during the year. Canada, Europe, Australia, and New Zealand will also take part in the trial.

In conjunction with the trial, all children in the U.S. who are diagnosed with Acute Myeloid Leukemia (AML) will be genetically screened as part of a synchronous study to track the clinical progress and outcomes of all children diagnosed with the disease. This data will be housed in a global data commons called INTERACT (INTERnational pediatric Acute myeloid leukemia ConsorTium). If a child relapses after initial treatment, that patient will be enrolled in the master trial and the data gathered through INTERACT will help inform the treatment in the trial. The

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INTERACT Data Commons will provide the largest ever dataset of pediatric leukemia, allowing researchers and physicians to identify patterns and benchmarks for treatment, assess and validate new data against past findings, and find new pathways for study.

The initiative has gained support from the Children's Oncology Group, which will help facilitate participation by medical sites that are part of the group. I noted that Morristown Medical Center was listed as a potential participant in the LLS PedAL trial. LLS is more than doubling its investment in pediatric research grants, bringing it to more than \$52 million in multi-year grants over five years. The emphasis is being placed on identifying the most high-impact projects with a clear bench-to-bed trajectory. The launch of the LLS Children's Initiative resulted in 22 new, major pediatric grants activated in FY20, six grants in FY21, and nine more grants in FY22 for a total of 37 grants thus far.

In addition to research, LLS provides much-needed support for patients and families, including educational materials, a robust Information Resource Center with master's-level oncology social workers, nurses and health educators, and financial assistance to help families meet the costs of treatment, travel, and basic expenses. LLS has also initiated a scholarship program to provide up to \$7500 to support tuition expenses for students attending two-year, four-year, or vocational programs. They will be awarded based on merit to blood cancer survivors who were diagnosed up to and including 25 years of age. The first scholarships will be awarded this spring.

LLS New Jersey's Board has some new faces, with four members cycling off (Guy Adami, Peter Cordua, Gregory Geissman and Christopher Pilla) and five new members joining the board (Sarah Cirelli, Joe Cupoli, Generosa Grana, MD, and Alexis Wolfson). The board makeup has gone from 2 women and 13 men in 2020-2021 to 6 women and 10 men in 2021-2022. There was no treasurer listed on the executive committee this year so not sure if it's an open position.

LLS National had a strong fiscal year in 2021, with an operating surplus of \$112.3M and unrestricted net assets totaling \$340 million. Net assets were buoyed by large increases in the fair value of investments. I recommend the budgeted \$100K.

JJK COMMENTS: Given the globe-spanning efforts of the PEDal trial – and the many large institutions associated with it – it is easy to lose sight of the individuals who will be affected by the work of LLS. For a family that has seen a child undergo not one but two relapses, I can only imagine the hope mixed with fear in learning about the PEDal clinical trial, approved by the FDA in January 2022. The trial is testing the efficacy of a therapy called venetoclax, which is designed for children with AML who have relapsed twice. As a “registration trial,” it is in the last step before the drug is approved for commercialization and coverage from health care plans. We can safely assume it has shown some promise. It is worth mentioning that, since twice-relapsed AML is rare, the need for a global trial is all the more pressing, so that an adequate sample size can be developed. All the more reason, then, for us to applaud the completed construction of the aforementioned INTERACT Data Commons, which will ensure that terms and data are entered in a universal language.

Complementing LLS's research and patient services pillars is their work on advocacy and policy. According to the proposal, LLS's advocacy efforts helped secure full funding of \$80 million for childhood cancer research programs (note that this is not *just* blood cancer) at the National Institutes for Health. Furthermore, in the coming year, LLS will advocate for steady government funding for pediatric cancer tissue biobanks and for streamlining access to out-of-state care for

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children with cancer. Sad that barriers would exist for children and families facing such terrifying challenges. Finally, LLS aims to stop insurance companies from discriminating against pediatric cancer survivors, whom “junk” insurance plans can shockingly revoke coverage mid-year. In addition to all of this work, of course, LLS continues to coordinate approvals from domestic and international regulators.

This grant would represent our fourth year of support for the LLS Children’s Initiative, which modeled itself after the Beat AML Initiative. The fact that LLS can use the lessons of the Beat AML initiative inspires confidence. Furthermore, the progress that we have seen over the last four years, in setting up the trial itself and now receiving approval from the FDA, means that lives are already being affected. There is reason to hope.

I recommend steady funding for LLS at \$100,000. LLS does an admirable job of making us feel connected to the research and the project.

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FM KIRBY FOUNDATION Financial Statement Analysis

Grantee Name:	The Leukemia & Lymphoma Society	Date:	3/21/2022
Prepared By:	DLK		
Grant Request Amt.	\$ 125,000	Type of Financial Report Submitted	Audit - National
Budgeted Amt.	\$ 100,000	Period Covered in Financial Report	6/30/2021
Audit Firm	KPMG	Date of Report Issuance	10/25/2021
Opinion	Present fairly		
Basis of Acctg.	GAAP		
Current Ratio (Liquidity Ratio/Working Capital Ratio)	5.07	Amount of Unrestricted Net Assets (Operating Reserve)	\$ 339,806 (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	6/30/2021	%	Must Read Financial Statement Notes
A. Program Service Expenses	\$ 274,701	74%	Ideally program expenses should be at least 70% of total budget.
B. Management and General	\$ 46,495	13%	
C. Fundraising	\$ 50,399	14%	
D. Total Expenses	\$ 371,595	100%	
	(in thousands)		

Comments/ Notes:

FY22 Budget: The National budget for FY22 is forecasting a \$21.5M surplus vs a surplus of \$110.3M for FY21. Total operating revenues are projected to decline by \$53.7M (11%), with co-pay contributions down \$34.4M (19%) and TAP contract revenues down \$11M (88%). Total operating expenses are budgeted to grow by \$35.1M (10%), with the biggest increases in research (up \$40.7M/64%) and supporting services (up \$6.4M) being partially offset by a decrease in patient/community assistance (down \$11.9M /7%).

The FY22 budget for LLS NJ is forecasting a \$5.5M surplus vs a \$5.8M surplus for FY21. Revenues are decreasing by \$153.6K (2%), while expenses are growing by \$122K (5%) with payroll/benefits up \$31.7K (2%), travel/meetings up \$59.5K, postage/shipping up \$24.5K (102%) and stationery/supplies up \$23K (247%).

FY21 Audit: (LLS National)

LLS had an operating surplus of \$112.3M for FY21 vs \$78.4M for FY20. Total net assets grew by \$151.5M vs \$99.5M in FY20 due to positive increases in the fair value of investments. Total operating revenues were relatively flat to FY20 (down \$2.9M/1%), with small growth in contributions (\$6.5M/3%), co-pay contributions (\$8.3M/5%) and legacy revenue (\$2.7M/32%) being offset by declines in TAP royalties (\$9.0M/42%), donated services (\$4.5M/50%), and service revenue (\$3.7M/23%). Total program services expense declined by \$43.4M (14%), with a large decrease in patient and community service of \$31.6M (this is where co-pay assistance resides) and a decline in public health education of \$21.1M (44%). Supporting services expense increased by \$6.5M (7%). LLS had investments totaling \$708.1M as of June 30, 2021, of which \$7.9M were endowment-related. There were no red flags as a result of my review.

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DISPOSITION:

- Declination
- Hold for review on/about:
- Approval for: **\$100,000**
- Hold for Board Review
- Insert Information: **Toward the LLS Children's Initiative**
- Other:

Initials: *JAK* Date: *4/6/22*
Check #: _____ Date: _____