

F. M. KIRBY FOUNDATION SOLICITATION EVALUATION FORM

DATE: April 4, 2024
Program Area: Health
Grant Type: Board Grant

REQUEST DATE: February 21, 2024

APPLICANT:
The Leukemia & Lymphoma Society, Inc.
14 Commerce Drive, Suite 301
Cranford, NJ 07016

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

AMOUNT REQUESTED: \$750,000
BUDGETED AMOUNT: \$250,000

NATURE OF REQUEST: Support of the Dare to Dream Project

GRANT HISTORY

SUPPORT: 1979-2023

OF APPROVED GRANTS: 36

TOTAL DOLLARS: \$3,440,000

LAST GRANT DATE: 05/01/2023

LAST GRANT AMOUNT: \$125,000

FYE DATE: 06/30/2023

AFS DATE: 11/06/2023

Year Approved	Approved Amount	Approval Date	Grant Purpose
2023	\$125,000	05/01/2023	Support of the Dare to Dream Project
2022	\$100,000	05/02/2022	Toward the LLS Children’s Initiative
2021	\$100,000	05/03/2021	Toward the LLS Children's Initiative
2020	\$100,000	04/29/2020	Toward the LLS Children’s Initiative
2019	\$100,000	04/15/2019	Toward the LLS Children’s Initiative

LAST SITE VISIT DATE: June 2020

ENDORSEE: N/A

FINANCIAL ANALYSIS COMMENTS: The FY24 expense budget for Leukemia & Lymphoma Society (LLS) National projects a 5% increase over the prior year actuals. The FY24 revenue budget projects a \$50.1M deficit, and a 4% decrease from the prior year actuals. The

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budget doesn't consider dividend/interest income, or assets released from restriction, which are reflected in the audited financial statements, but I still see a somewhat concerning trend of continued deficits and asset reduction, so I reached out to Advancement Director Matt Mastriani for additional background. This is the answer I received: *"The decrease in revenue from FY23 to FY24 is directly attributable to two things: a) The expected decrease in our Co-Pay Program, which is 100% funded by pharmaceutical donors. Due to recent gov't regulations and other external factors, LLS has projected that there will be an industry wide decrease in this area. b) As a general rule, LLS does not budget for interest income on investments as it is not part of our normal operations. In FY23, the Organization received \$11M in interest from our investment holdings. Then regarding the deficit and how do we intend to cover that deficit: Due to our strong balance sheet and net asset position driven by prior year surpluses, LLS Management and the Board of Directors have proactively decided to increase our investment into our Mission and purposefully deficit spend. This deficit spend is focused primarily on the Mission activities of the Organization, including but not limited to increase our research grants, financial assistance, and other mission activities. The Organization manages and reviews our spend on a monthly, quarterly, and annual basis with set goals for our Organization from a FY perspective as well as the strength of our balance sheet. In the upcoming years, the Organization will adjust the spending levels as needed to ensure that we continue to be a strong financial position and ensure the long-term success of the Organization and our Mission."* The FY24 expense budget for LLS NJ projects a 9% decrease from the prior year actuals. The FY24 revenue budget projects a \$7.2M surplus, and a 13% decrease from the prior year actuals – as a National organization, all donations in the local regions are funneled and centralized to the National Office, which then utilizes those funds to execute LLS' mission, pay bills and employees, etc. It is difficult to do an apples-to-apples comparison to FY23, as the FY24 budget no longer includes revenue or expenses associated with Athletics Initiatives or Direct to Consumer Campaigns. These items are now planned for at the National level of the organization. The FY23 National audit shows unrestricted net assets totaling \$288M, and a cash position of \$2.8M – a decrease of \$8.1M from FY22's cash position. Investments are valued at \$590.5M, with \$203.6M held for the patient Co-Pay Program. Total endowment value is \$8.2M, a 6% increase over FY22. Financial assets available for general expenditures within 12 months are \$370.7M. As per the FY23 audit, supporting services represented 26.1% of functional expenses. FMKF last approved a grant to LLS in FY23. The amount accounted for 1.24% of the New Jersey region's total revenue.

ORGANIZATION DESCRIPTION: The Leukemia & Lymphoma Society (LLS) was born out of a family's grief following the death of their teenage son. Robbie Roesler de Villiers was only 16 when he succumbed to leukemia in 1944. Five years later, frustrated by the lack of effective treatments for what was then considered a hopeless disease, his parents started a fundraising and education organization in their son's name. Despite most leukemia patients, especially children, dying within three months, the de Villiers believed that leukemia and other blood cancers were curable. Driven by that belief, and the memory of Robbie, they grew the organization from a small Wall Street office to its first chapters in the New York City area, and eventually an entity with a global reach. Dedicated to curing leukemia, lymphoma, myeloma, and other blood cancers, that organization is now known as LLS, the world's largest nonprofit health organization dedicated to funding blood cancer research and providing education and patient services. Since 1949, LLS has invested nearly \$1.7B in groundbreaking research, pioneering many of today's most innovative treatments – LLS helped advance 70% of the blood cancer treatment options approved by the FDA since 2017. The cumulative effect of LLS' 75 years of investment in better treatments is profound: blood cancer mortality has declined 32% over the past three decades and continues to drop. Looking ahead, LLS intends to continue leading the way toward cures!

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LLS recently underwent a significant leadership change, as President and CEO, Dr. Louis DeGennaro, retired after 18 years at LLS (8 as CEO), and E. Anders Kolb, M.D., took the helm as LLS's new President and CEO as of May 1, 2023. As a world-renowned pediatric hematologist/oncologist, Dr. Kolb has dedicated his career to treating blood cancer patients and conducting research to find cures. Before joining LLS, Dr. Kolb was Chief of the Division of Hematology and Oncology of Nemours Children's Health, Delaware Valley, Director of the Moseley Foundation Institute for Cancer and Blood Disorders, and Vice Chairman for Research in the Department of Pediatrics at the Sidney Kimmel Medical College at Thomas Jefferson University. While new in this role, Dr. Kolb is not new to LLS. Indeed, Dr. Kolb served as co-chair of the LLS PedAL Master Clinical Trial from its inception. While Dr. Kolb stepped down from this role when he became CEO of LLS, he continues to be involved with and champion PedAL and the broader Dare to Dream Project as LLS's CEO. JJK and I had the honor of meeting Dr. Kolb in October 2023, when FMKF was presented with the New Jersey Chairman's Award – the region's highest honor presented to an individual, group of individuals, foundation or corporation that has displayed a steadfast commitment to LLS that far extends beyond the score of what is typical.

EMILY PRINCE COMMENTS: In FY24, LLS is seeking a multi-year grant of \$250K per year for up to three years, or up to \$750K total, in support of the Dare to Dream Project. The Dare to Dream Project is a 5-year, \$175 million comprehensive initiative that is taking on pediatric cancer from every angle and through every facet of LLS' mission. This holistic approach is part of the "special sauce" that makes this endeavor so unique and so effective – LLS is not only advancing new therapies for children with blood cancer, but also working to ensure that patients can access them, and that families have all the support they need to face the many challenges that accompany a child being diagnosed with cancer. Targeted support has enabled LLS to make significant progress across all aspects of the Dare to Dream Project since its official launch in 2022, including in Research, Patient Support, and Policy Advocacy.

Research: Through the Dare to Dream Project, LLS is (1) investing in the most innovative and promising pediatric blood cancer research projects across the globe; (2) leading a groundbreaking global Pediatric Acute Leukemia (PedAL) Master Clinical Trial; and, (3) funding the development and opening of the first global pediatric acute myeloid leukemia (AML) data commons.

1. To speed breakthroughs, through Dare to Dream, LLS is doubling its investment in pediatric research grants, with a focus on driving novel drug discovery and development through a deepened understanding of the mutations and molecular aberrations unique to pediatric patients. Children are not little adults; cancers behave differently in children than adults. Children need therapies designed just for them, targeted to their unique biomarkers. LLS' goal is to develop precision medicines that cure without lifelong complications, as up to 80% of pediatric patients experience chronic health issues from taking the harsh chemotherapies that are today's standard of care. Through Dare to Dream, LLS currently has nearly 30 active research grants focused specifically on childhood blood cancer, comprising an investment of more than \$22 million.
2. LLS launched the PedAL Master Clinical Trial in April 2022 and currently have the PedAL screening trial and one therapeutic sub-trial open and enrolling patients, a second therapeutic sub-trial focused on patients with AML and acute lymphoblastic leukemia poised to open in the next several months, and several more therapeutic sub-trials in development. As a reminder, the screening trial is the portal of entry into the PedAL trial

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and provides genomic screening to every patient so they can be matched with a therapy that is right for their disease subtype. The screening trial is currently open at 175 medical centers across the United States (including 6 centers in New Jersey), Canada, Australia, and New Zealand, and has enrolled 246 patients. There is a parallel screening mechanism, called a Registry, which is enrolling patients in Europe. As a point of reference, when LLS applied to FMKF one year ago, the screening trial was open at 143 sites only in the U.S. and Canada, and 73 patients had enrolled. More important than the number of patients enrolled is what it represents: With PedAL, LLS is making vital genomic screening, which is the very foundation of precision medicine, accessible to more patients by removing the barrier of cost. Beyond the screening trial, the first PedAL therapeutic sub-trial is currently open at 70 medical centers worldwide (vs. 22 centers one year ago) - including Morristown Medical Center - and 26 patients have enrolled to date. This is a significant accomplishment because every country has its own regulatory process, requiring separate submissions and approvals.

3. The Data Commons, designed to gather and house all genomic and clinical data for every child diagnosed with AML, just “went live” on January 30, 2024, a major milestone for the Dare to Dream Project! That means the Data Commons is now officially open to scientists worldwide who can access and utilize this never-before-available compilation of global data to fuel their investigations into pediatric AML, accelerating research toward cures for this deadly disease. This is the culmination of substantial work over the last several years - first to develop a “data dictionary” establishing a common, universal language for all the data to be housed, then gathering data from multiple institutions and AML cooperative groups worldwide, then translating and harmonizing that data pursuant to the data dictionary, then quality-control checking all the harmonized data and, finally, merging all of that data into the Data Commons. The Data Commons is currently comprised of data gathered from St. Jude’s Children’s Research Hospital, the Children’s Oncology Group, Japan Children’s Cancer Group, and Berlin-Frankfurt-Munich, a German consortium. The next data additions are expected to come from Dutch, Nordic, and Austrian groups, as well as data gathered from patients enrolled in the PedAL trial. We are seeing data sharing more prominently in our health docket, and I am pleased that it figures so heavily in the Dare to Dream Project.

Patient Support: Through the Dare to Dream Project, LLS continues to expand the depth and breadth of support programs and resources offered to patients and their families. New developments over the past year include: (1) awarding 105 new Scholarships for Blood Cancer Survivors and renewing 71 scholarships for prior recipients, enabling them to either start or continue their post-secondary education. Scholarships provide up to \$7,500 to support tuition expenses and can be renewed every year the student remains eligible. To date, LLS has awarded a total of 276 scholarships (including 71 renewals) through this program, including 12 scholarships to New Jersey students. In 2024, they intend to award 100 new scholarships and renew all eligible scholarships; (2) launching a new Teen’s Guide to Everything Cancer, which provides guidance on self-advocacy and self-care for teens during and after cancer treatment. Topics covered include navigating healthcare, managing side effects, school, mental health and body image, nutrition and movement, and survivorship. The guide is available printed or online, in English and in Spanish. Since LLS launched this new magazine in August 2023 at CancerCon, an annual gathering of hundreds of adolescents and young adults affected by cancer, more than 3K printed copies have been ordered and the online version has received nearly 900 views; and, (3) awarding \$2.9M in

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financial assistance, including nearly \$40K in New Jersey, helping patients and their families with expenses like travel, rent or mortgage, food, utilities, transportation, child- or elder-care, and more. All of this is in addition to ongoing services such as the Clinical Trial Support Center, where pediatric oncology nurse navigators help families locate and enroll in clinical trials for patients and YAConnect Young Adult Online Chat, where patients can connect and share about having been recently diagnosed or living with a blood cancer.

Policy Advocacy: Through Dare to Dream, in 2023, LLS elevated their voices to advocate for legislation to improve access to care for pediatric patients and for sustained federal funding for pediatric cancer research. They did so through a variety of means, including an advocacy day in Washington, DC in May and through the much larger inaugural Dare to Dream Summit in October, where they brought nearly 300 advocates to Washington, DC to: (1) urge members of Congress to co-sponsor the Accelerating Kids' Access to Care Act (AKACA); and (2) urge Congress to retain federal financial support for two existing research programs that currently provide \$80M to fund pediatric cancer research, including programs that focus on survivorship. The AKACA is essential legislation for kids with cancer, who often need specialized care requiring them to travel outside their home state. However, doing so currently requires bureaucratic steps that can cause dangerous delays in treatment, especially for the 50% of kids covered by Medicaid or the Children's Health Insurance Program (CHIP). The bipartisan AKACA would reduce the paperwork required of doctors treating children from out-of-state, streamlining the process and enabling kids to get treatment faster. LLS's efforts resulted in 45 new lawmakers signing on to co-sponsor the AKACA. In the coming year, LLS intends to build off this momentum to address the challenges faced by pediatric patients in securing new, better treatments by advocating to prevent the FDA from drastically reducing investment in pediatric cancer therapies.

It is shocking to me that pediatric cancer isn't given more attention by the pharmaceutical industry and federal government. From a practical perspective, children grow up to be adults, who are both consumers and taxpayers, so there is an economic benefit to keeping them healthy and alive. From a more emotional perspective, who can stomach the idea that children are suffering from these terrible diseases and toxic treatments, and not want to make it their life's mission to eradicate them? Thankfully that is precisely what LLS is dedicated to doing – investing in the development of better treatments, which will lead to cures and a better quality of life for patients and their families.

Since February 2023, DLK and I had two calls with LLS about the possibility of multi-year support for the Dare to Dream Project, and both are documented in Giving Data. LLS also shared project materials and a draft request for consideration. This is all to say that this multi-year request is not unexpected or surprising in its length or amount, and was carefully considered internally over the last year by program staff and senior leadership. FMKF has been supporting LLS since 1979, to the tune of \$3,440,000, and the Dare to Dream Project (and its precursor, the Children's Initiative) since 2019. A three year pledge of \$750K will provide LLS with a sustained, consistent source of funding upon which they can rely to plan the future growth of Dare to Dream and to reach their objectives. Additionally, a multi-year pledge could inspire others to do likewise – as of 2/22/2024, the Dare to Dream Project has raised \$88.3M from more than 300 individuals and foundations, 61 of whom have committed to a multi-year pledge. Given our longstanding relationship with LLS and the Dare to Dream Project, it is fitting that we would consider a multi-year grant to close out

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the last three years of the initiative and provide them with funds upon which they can rely, plan, and grow. Therefore, in FY24, I recommend a 3-year grant of \$750K in support of the Dare to Dream Project.

RECOMMENDATION: In FY24, I recommend a 3-year grant of \$750K in support of the Dare to Dream Project, payable as follows:

FY24: \$250K

FY25: \$250K

FY26: \$250K

JUSTIN J. KICZEK COMMENTS: Over the past five years, we have watched this program come into being. How exciting it is to hear of the many families enrolled in the PedAL screening trials, without regard to whether or not they can pay for the testing, considering that LLS is making it cost-free.

This is a significant, multi-year investment in multiple pillars of their work. I appreciate the fact that, through this grant, we are not just investing in research, but also in the data infrastructure that can improve researchers' collaborations across borders. The Data Commons, now "live," vastly improves LLS's ability to trace patterns of blood cancers and treatments and continue to save lives.

The stewardship from this organization has been excellent; it does seem high time for us to consider a larger, multi-year investment for this organization.

That said, after further conversation with Emily, I recommend a lower amount of \$500K in total, over three years. With several important initiatives coming to a head in the years to come, we wanted to leave more oxygen in 2025 and 2026. That said, this amount, spread out over three years, would still be well above what FMKF has granted to LLS over similar time periods in previous years and would still represent a significant investment in this organization and this initiative. We recommend a higher amount this year, as we had already built it in to our budget.

RECOMMENDATION: I recommend a three-year grant of \$500,000 in support of the Dare to Dream Project payable as follows:

FY24: \$250K

FY25: \$125K

FY26: \$125K

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DISPOSITION:

- Declination
- Hold for review on/about:
- Approval for: **\$500,000**
- Recommended Grant Payment(s):
2024: \$250,000
2025: \$125,000
2026: \$125,000
- Hold for Board Review: **April 26, 2024**
- Payee Other Than Addressee:
- Insert Information:
- Other:
Include multi-year grant letter.

Initials: JK

Date: 04/11/2024

Check # _____

Date: _____