

F. M. KIRBY FOUNDATION SOLICITATION EVALUATION FORM

DATE: February 12, 2024

REQUEST DATE: January 23, 2024

Program Area: Health

Grant Type: Board Grant

APPLICANT:

Alzheimer’s Disease and Related Disorders Association, Inc.
225 North Michigan Avenue, 17th Floor
Chicago, IL 60601-7633

CONTACT: Ms. Laura Fruge, Executive Donor Advisor

AMOUNT REQUESTED: \$200,000

BUDGETED AMOUNT: \$125,000

NATURE OF REQUEST: Support for early-career investigators through the International Research Grant Program

GRANT HISTORY

SUPPORT: 1984-2023

OF APPROVED GRANTS: 36

TOTAL DOLLARS: \$8,431,413

LAST GRANT DATE: 05/01/2023

LAST GRANT AMOUNT: \$125,000

FYE DATE: 06/30

AFS DATE: 10/23/2023

Year Approved	Approved Amount	Approval Date	Grant Purpose
2023	\$125,000	05/01/2023	Support for Early-Career Investigators through the International Research Grant Program
2022	\$125,000	05/02/2022	Support for Early-Career Investigators through the International Research Grant Program
2021	\$125,000	05/03/2021	Support for Early-Career Investigators through the International Research Grant Program
2020	\$125,000	04/29/2020	Support for Early-Career Investigators through the International Research Grant Program
2019	\$150,000	04/15/2019	Support for Early-Career Investigators through the International Research Grant Program

LAST SITE VISIT DATE: August 2020

APPLICANT: Alzheimer's Association/National Office

ENDORSEE: N/A

FINANCIAL ANALYSIS COMMENTS: The FY24 expense budget for the Alzheimer's Association (the Association) projects a 3% decrease from the prior year actuals. Most of the decreases are attributable to care, support, and risk reduction and public policy line items. Research, which FMKF funds, is projected to increase by \$400K. The FY24 revenue budget projects staying flat over the prior year actuals, with a \$9.9M deficit after investment gains. This is an improvement over FY22, which ended with a \$26.9M deficit after investment gains. The FY23 audit shows unrestricted net assets totaling \$145.8M, and a cash position of \$33.8M. Investments are valued at \$293.7M, a \$24.6M decrease from FY22. Total endowment value is \$16.1M. Total assets have increased by 4% from FY22. Financial assets available for general expenditures within 12 months are \$312.2M. As per the FY23 audit, supporting services represented 21.7% of functional expenses. FMKF last approved a grant to the Association in FY23. The amount accounted for less than 1% of all contributed income and 1.3% of foundation relations income.

ORGANIZATIONAL DESCRIPTION: Founded in 1980, as the Alzheimer's Disease and Related Disorders Association, the Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support, and research. Their mission is to lead the way to end Alzheimer's and all other dementia – by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Their vision is a world without Alzheimer's and all other dementia. Alzheimer's is the seventh leading cause of death in the United States, and one in three seniors dies with Alzheimer's or another dementia. More than 6M Americans are living with Alzheimer's today, and by 2050, the number is projected to increase to nearly 13M nationwide. Given that the fastest growing population in the United States and most of the developed world is individuals 65 and older, there is an urgent need to address the problem of cognitive aging, and thankfully the Association is up to the task.

In January 2023, Joanne Pike succeeded Harry Johns as Association President and CEO, becoming the first woman to hold these positions in the organization's history. Since joining the Association in 2016, Dr. Pike has held several roles, including Chief Programs Officer, Chief Strategy Officer, and President. Dr. Pike is also CEO of the Alzheimer's Impact Movement, a separately incorporated advocacy affiliate working to advance and develop policies to overcome the disease. Prior to joining the Association, Dr. Pike spent 13 years at the American Cancer Society. She holds a doctorate in public health leadership focused on health policy and management from the University of North Carolina at Chapel Hill.

The Association is the world's largest nonprofit funder of Alzheimer's and dementia research, with chapters across the country and a home office in Chicago. With support from philanthropic partners, they establish foundations that lead to milestone advancements; they convene scientists and other stakeholders to facilitate collaboration; and they advocate for increased government funding to accelerate research. When the Association was founded, the National Institutes of Health (NIH) invested \$13M in Alzheimer's research; in 2023 it totaled more than \$3.7B (**JJK: Astounding!**). This dramatic expansion in public funding requires an equally dramatic increase in projects to feed the pipeline. In 2023, the Association committed more than \$100M in a single year to accelerate research for the first time – this figure includes conferences and other scientific meetings and salaries for their Medical and Scientific Relations team. Active Association

APPLICANT: Alzheimer's Association/National Office

commitments totaling more than \$360M are powering more than 1K projects in 53 countries to achieve progress in treatment, prevention, early detection, risk reduction, and care.

EMILY PRINCE COMMENTS: The request highlights how a new era of Alzheimer's therapy has begun with FDA approval of two treatments that can slow the progression of mild Alzheimer's by targeting the protein that accumulates abnormally to form the hallmark "plaques" of Alzheimer's, and it is expected to take regulatory action on a third in 2024. Unfortunately, since this submission, the drugmaker Biogen announced that it will give up its ownership of Aduhelm and terminate an ongoing post-approval clinical trial that the FDA ordered to confirm the drug's benefit in people with early-stage disease. Biogen will now be prioritizing Leqembi, another drug based on the same science as Aduhelm. Biogen's decision to move on from Aduhelm is another twist in a saga surrounding what was hoped to be a blockbuster treatment, but ended up being one controversy after another when it was granted accelerated FDA approval in 2021 despite scant evidence of its efficacy and concerns around serious side effects including brain bleeding. The drug hit the market with a \$56K price tag, but was only covered by Medicare for patients in clinical trials, making it largely inaccessible to the average patient. I do not bring this up to knock the Association's important contributions to the science that brought about Aduhelm, or even really to knock Aduhelm itself – which was the first treatment to target the disease's underlying biology – just to note that despite billions of dollars and years of steadfast scientific commitment, there is still much work to be done to cure this terrible disease (**JJK: Great point.**). The Association issued a brief press release in response to the announcement, which can be found [here](#).

The Association identifies and funds high-potential research geared towards the following outcomes: increasing knowledge of disease biology; improving diagnosis, interventions, and disease monitoring; preventing cognitive impairment and dementia by developing drugs and lifestyle interventions; and slowing or stopping dementia via research and human trials. Grants are open to international and U.S.-based researchers and span all stages of a scientific career from postdocs to clinician scientists. In recent years the Association has been increasing its commitment to the professional development of early-career scientists in order to grow a workforce that is ready to meet the many challenges presented by dementia, now and in the future. They have also been increasing their support for diverse scientists from underrepresented communities. In 2023 the Association awarded 271 grants totaling \$74.5M – including 172 grants to early-career investigators. These awards help to attract and retain the best and brightest to the field, with 60-77% of all U.S.-based awardees obtaining follow-on funding within five years of receiving an Association award.

The request provided updates on Stephanie Schultz, Ph.D., Monica Maria Diaz, M.D., and Gabor Egervari, M.D., Ph.D., whose research has been previously supported by FMKF. Dr. Schultz recently obtained a five-year grant totaling \$129,166 to date from the NIH to further her work studying how different genetic variations of the gene PS1 may impact the accumulation of plaques. Dr. Diaz is continuing her work to develop a novel method of determining an individual's risk for cognitive decline based on social determinants of health in two distinct communities in Lima, Peru. And lastly, Dr. Gabor's team completed their study of the protein ACSS2 and its role in regulating how genes related to learning and memory are "turned on" and "turned off" during Alzheimer's. The findings may lead to further investigations of ACSS2 as a therapeutic target for the disease.

APPLICANT: Alzheimer's Association/National Office

In FY24, the Association is seeking a grant for \$200K to support research grant awards for early-career scientists from underrepresented diverse communities. Specifically, they are suggesting sponsorship of Xiaqing Jiang, PhD., a Postdoctoral Fellow at University of California, San Francisco for an investigation titled “Vascular Risk, Blood Biomarker, and Brain Health in a Tri-Ethnic Population.” Dr. Jiang’s research aims to shed light on how vascular risk factors contribute to the brain changes associated with Alzheimer’s and how genetic and other factors contribute to this process, particularly in racial and ethnic groups most at risk. While I find Dr. Jiang’s research fascinating, I echo DLK and JJK’s concerns and questions from last year regarding the Association’s criteria for its diversity grants – meaning, they do not define said criteria or explain how they outreach to those communities. An example being that one diversity fellow presents as a white woman – is the diversity that she is a woman, or is she perhaps neurodiverse? With the exception of the American Cancer Society, our early career research grants have not traditionally been earmarked for a specific researcher, but rather for a fellowship broadly. I suggest we take that approach with the Alzheimer’s Association in FY24 and broadly target support for early-career investigators through the International Research Grant Program. Presumably, that allocation would provide flexibility to award grant dollars to where they are needed most, whether it be to Dr. Jiang or another worthy applicant.

To keep pace with rising costs, in 2023, the Association increased the amount of most of its grants to a maximum of \$200K to \$250K over two to three years, meaning an approval of \$125K as budgeted in FY24 would fund exactly half of a grants’ maximum amount. Therefore, in FY24, I recommend an approval of a \$125K grant in support of early-career investigators through the International Research Grant Program. I would like to see FMKF get to a point where we are fully funding these fellowship commitments, though I do not see that as being a possibility in this fiscal year, since Scheie Eye Institute and Kennedy Krieger have returned after skip years and we will be considering large increases to Leukemia and Lymphoma Society and JDRF for campaigns. I will be mindful of this intention when budgeting in FY25.

RECOMMENDATION: In FY24, I recommend a grant of \$125K in support of early-career investigators through the International Research Grant Program.

JUSTIN J. KICZEK COMMENTS: While we have made strides in understanding and potentially mitigating Alzheimer’s (with the Leqembi treatment), it remains a devastating disease and one that is particularly painful for family of those with Alzheimer’s. The request notes that more than 11 million Americans are providing care to family members and friends with Alzheimer’s or dementia, with the value of this unpaid care coming in at \$340 *billion* in 2022. Projections suggest this could rise to nearly \$1 *trillion* in today’s dollars by 2050, if the preponderance of Alzheimer’s cases reaches the aforementioned projection of 13M. In addition to the lives lost and the pain of decline in later years, we have to consider here both the health care costs and the losses of economic productivity implicit for both patient and caregiver.

While Aduhelm and Leqembi share some controversy and some limited efficacy, the very fact that the treatments have reached a clinical stage represents a significant achievement. Our grants to AA help further develop our understanding of the disease, the potential bench-to-bedside treatments, and further preventative steps to delay the onset of Alzheimer’s.

APPLICANT: Alzheimer's Association/National Office

RECOMMENDATION: I recommend \$125,000 in support of early-career investigators through the International Research Grant Program.

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DISPOSITION:

- Declination
- Hold for review on/about:
- Approval for: **\$125,000**
- Recommended Grant Payment(s):
2023:
2024:
2025:
- Hold for Board Review: **April 26, 2024**
- Payee Other Than Addressee:
- Insert Information: **Support of early-career investigators through the International Research Grant Program**
- Other:

Initials: JK

Date: 03/27/2024

Check # _____

Date: _____