# F. M. KIRBY FOUNDATION SOLICITATION EVALUATION FORM

**DATE:** November 19, 2023        **REQUEST DATE:** October 30, 2023

**Program Area:** Health

**APPLICANT:**

Autism Speaks, Inc.
1060 State Road, 2nd Floor
Princeton, NJ 08540

**CONTACT:** Ms. Billie Cipriano, Sr. Director, Foundation & Grant Relations

**AMOUNT REQUESTED:** $130,000        **NATURE OF REQUEST:** PATH to Discovery Program

## GRANT HISTORY

**SUPPORT:** 2020-2022

**# OF APPROVED GRANTS:** 3        **TOTAL DOLLARS:** $120,000

**LAST GRANT DATE:** 12/22/2022        **LAST GRANT AMOUNT:** $40,000

**FYE DATE:** 03/31        **AFS DATE:** 09/22/2023

| Year Approved | Approved Amount | Approval Date | Notes |
|---|---|---|---|
| 2022 | $40,000 | 12/22/2022 | Toward the Early Career Fellowship program focused in translational science |
| 2021 | $40,000 | 12/17/2021 | Toward the Early Career Fellowship program focused in translational science |
| 2020 | $40,000 | 09/30/2020 | Toward the Early Career Fellowship program focused in translational science |

**HELEN BENSON COMMENTS:** See financial analysis.

**EMILY PRINCE COMMENTS:** I had the opportunity to meet with representatives from Autism Speaks this past August at the FMKF offices. Knowing there was waning enthusiasm for this grantee in past years, I wasn't sure what to expect going into the meeting, but I came out of it feeling very positive about the organization and its work. I have those same feelings of positivity after reviewing their grant request for the PATH to Discovery program – <u>P</u>ersonal <u>A</u>utism <u>T</u>reatments for <u>H</u>ealth, and enthusiastically recommend support in FY23 and beyond.

Autism Speaks is dedicated to creating a world that is inclusive of individuals with autism, which they do through advocacy, support services, research, and education. Autism, or autism spectrum

disorder (ASD), is a developmental disability caused by differences in the brain. For some people, there is a known genetic component that causes that difference while for others the causes are still unknown. There are many subsets of autism, with about 15% being predictable from genetics, and the rest being idiopathic (which means spontaneous or from an unknown cause) and multifactorial – essentially, the latest thinking amongst scientists is that there are multiple causes that act together to change the most common ways people develop, and we still don't know why exactly this results in ASD for some portion of the population. There are now 135 identified autism genes, twenty-seven of which are new to autism.

PATH builds upon the scientific work of Autism Speaks and its predecessor organizations over the last 25 years to ensure that one day, each person diagnosed with autism will have a personalized treatment plan – unique and customizable across their lifetime. Over the last two decades, Autism Speaks has made significant investments in the field of autism research and treatment through its genomic initiatives, Autism Genetic Resource Exchange (AGRE) and MSSNG (pronounced "missing"). AGRE is the largest private, open-access repository of clinical and genetic information dedicated to autism research. MSSNG is a global open-source database that provides whole genome sequencing of blood DNA of 12K+ individuals from families from the AGRE repository and other cohorts. These visionary efforts allowed the field to utilize whole genome sequencing in autism to unlock DNA secrets and guide new understandings and treatment targets. PATH combines the clinical and genetic data of AGRE with the genomic sequenced data of MSSNG to advance the fields ability to: increase early detection of autism risk; identify autism sub-groups; and inform autism treatment protocols. PATH is an unprecedented integration of Artificial Intelligence (AI), clinical networks, genomic, clinical, and biological data to discover new findings and build a program by which discoveries can ultimately give back to clinics to guide health care and treatments.

Since the pilot launched, PATH's data transfer infrastructure was built and 6 clinical sites were recruited from the existing Autism Care Network (ACNet) to enroll 100 families in total to collect broader and deeper information not only on their behaviors, but also on their biology to teach the researchers how autism begins, develops, and is responsible for the spectrum of autistic traits. Families will share this biological information through blood samples, which is then connected to behavioral and advanced biological data, as well as health issues monitored by their healthcare providers. Taking advantage of the ACNet footprint allows more individuals and families to enroll, thus expanding the scope and scale of the data and findings. These larger datasets increase the ability for researchers to find patterns and connections in groups of diverse individuals. Another exciting update is that Stanford University has come on as a key partner. Dr. Michael Snyder, Chair, Department of Genetics and Director, Center for Genomics and Personalized Medicine at Stanford School of Medicine and his team will conduct analysis on blood samples that will investigate how autism changes the reading of DNA, metabolism, proteins, lipids, and how cell signaling, and the immune system are affected. An important part of PATH will be coupling these measurements to the clinical assessments.

A critical part of advancing autism science is data sharing, which is evidenced by both PATH and MSSNG. Autism Speaks will be looking to expand the impact of its programs, and hopefully benefit from the work of others, by participating in two international programs to share and analyze data – the Global Alliance for Genomics and Health and Canadian Platform for Genomics and

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Precision Health (CP4GPH). Each of these efforts are aimed at understanding data sharing needs and issues on an international landscape, along with developing advanced cloud computing to build federated networks to aggregate larger data sets to accelerate understanding of the complexities of autism and personalized healthcare.

The PATH phase 1 budget is $12.1M over 5 years and is invested across multiple elements, including informatics; whole genome sequencing; MSSNG platform expansion; ACNet site selection and management; and cloud storage and portal maintenance. To lead them to their phase 1 fundraising goal, a generous supporter, Gordon Gund of Princeton, New Jersey in memory of his wife Llura, has initiated a challenge by pledging to give $2.15M if Autism Speaks can raise $4.3M by December 2023. Towards this $4.3M challenge goal, Autism Speaks has raised $2.88M.

We are seeing a shift in our health docket towards precision medicine – the use of research and analyses unique to an individual that informs their treatment plan – and this could be another opportunity for FMKF to make an impactful investment – both from a scientific standpoint and from a financial standpoint because of the Gund match. Raising Autism Speaks from the budgeted $40K to $60K in FY23, would put it on par with Crohn's & Colitis, a similarly situated organization in the docket, and consistent with a broader strategy of making fewer, larger grants. By recommending a multi-year commitment of $120K - $60K in FY23 and $60K in FY24 – we are recognizing the importance of long-term planning and financial stability when launching major initiatives and allowing additional funds to be allocated towards the Gund match – multi-year commitments are considered eligible, so long as they are pledged prior to the expiration of the match deadline. Therefore, I recommend a multi-year commitment to Autism Speaks of $120K towards the PATH to Discovery program, payable as follows: $60K in FY23 and $60K in FY24.

**JUSTIN J. KICZEK COMMENTS:** This proposal reminds me in some ways of the PEDal research project we funded with LLS in that it seeks to create a massive and international genomic data commons, with the aim to develop better interventioned and more personalized therapeutics. Here, the project benefits from Autism Speaks scale and reputation, as it appears they have clearly leveraged these advantages in order to bring more partners on board, such as Stanford. Given many of the mysteries that remain about autism, I find this research into the genomic drivers of ASD to be worthy of philanthropic investment. ECP, any idea why they receive so little government support? I would think a data project like this should be able to attract more government research funding. **(ECP: JJK, my limited and evolving understand of this space is that government funding would likely go to the ACNet sites, as opposed to Autism Speaks itself. The latest federal funding bill included funding for special education services, mental healthcare, vocational training, and increased research dollars. Autism Speaks exists to advocate for the autism community in Congress and fill gaps in research, patient support, and other areas, so it isn't surprising to me that they wouldn't be a recipient of government funding. That said, it is a good question, and I will follow up with them on it.)**

I think ECP's suggestion is great here, considering the Gund challenge and the attractiveness of this data project. I recommend $120K, as designated below.

**APPLICANT:** Autism Speaks, Inc.

| FM KIRBY FOUNDATION | | | | | |
|---|---|---|---|---|---|
| **Financial Statement Analysis** | | | | | |
| **Grantee Name:** | Autism Speaks | | **Date:** | | 11/15/2023 |
| **Prepared By:** | HVB | | | | |
| | | | | | |
| **Grant Request Amt.** | $130,000 (over 2 years) | | **Type of Financial** | | |
| **Budgeted Amt.** | $40,000 | | **Report Submitted** | | Audit |
| | | | **Period Covered** | | |
| | | | **in Financial Report** | | March 31, 2023 and 2022 |
| **Audit Firm** | Grant Thornton | | | | |
| **Opinion** | Present Fairly | | **Date of Report** | | |
| **Basis of Acctg.** | GAAP | | **Issuance** | | 9/22/2023 |
| | | | | | |
| **Current Ratio (Liquidity Ratio/Working Capital Ratio)** | | | **Amount of Unrestricted Net Assets (Operating Reserve)** | | |
| | 1.48 | | | | $23,467,919 |

**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** | 3/31/2023 | | **%** | | |
|---|---|---|---|---|---|
| | | | | | |
| **A. Program Service Expenses** | $  70,601,543 | | 86% | | Ideally program expenses should be |
| **B. Management and General** | $   3,304,786 | | 4% | | at least 70% of total budget. |
| **C. Fundraising** | $   7,976,836 | | 10% | | |
| **D. Total Expenses** | $  81,883,165 | | 100% | | |

**Comments/ Notes:**

**Budget 2024:** For 2024, Autism Speaks Inc. is projected to have a deficit of $2.5M versus a $8.0 deficit in the fiscal year ended 2023. Budgeted Public Support/Revenue is forecasted to grow $14.7M over 2023 while Program Sevices are anticipated to increase by $10.1M. General and Administrative Expenses will remain relatively flat at $3.6M or 3.9% of the total expenses.

**FY Audit 2023 (Mar 2023):** Autism Speaks had a net $8.0M deficit in Net Assets as of March 31,2023, versus a surplus of $2.1M in 2022. The $10.1M decrease year over year is primarily attributed to a $21M decrease in Revenue as a result of decreases in the following: In-kind Contributions and Donated Services:$11M, Gifts and Contributions:$4M, Other Income :$2.8M and Government Grants:$1.8M. This decrease in revenue was offset by a decrease in total expenses of $11M primarily attributed to a decrease of Program Service expenses of $11.5M offset by an increase in Supporting Services of $570K.

The organization currently has all of its available funds in cash and cash equivalents ($31M) held in financial institutions and in excess of the FDIC limit which is noted as a concentration of credit risk in the Notes to the Financial Statements . However, management does not perceive there to be any significant risk associated with this. Also worth mentioning is that the organization has reserved $25M which has been designated by the Finance and Investment Committee as operating reserves for 2023 and 2022. This amount reduces the total available funds for general use within one year of the consolidated statement of financial position date of March 31 for each 2023 and 2022, respectively. The organization has a line of credit available through 2028 for which it can borrow $1.5M but there is no balance outstanding at March 31,2023. There are no red flags noted as a result of the financial review.

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**DISPOSITION:**

( ) Declination

( ) Hold for review on/about:

(X) Approval for: **$120,000**

(X) Recommended Grant Payment(s):
**2023: $60,000**
**2024: $60,000**

(X) Hold for Board Review

( ) Payee Other Than Addressee:

(X) Insert Information: **Support of the PATH to Discovery Program**

(X) Other: **Enclose Multi-Year Grant Letter with Check**

Initials:_____ Date: 11/29/2023

Check #_____ Date:_____