#### **ARTZ in the Neighborhood:**

#### Revising and Continuing a Community-Driven Program Development Project By and For People Living with Dementia and Their Care Partners, Under the Influence of Lessons Learned During the Pandemic

#### **Executive Summary:**

We are seeking support from Friends Foundation for the Aging in the amount of \$32,500 to continue our program development project "ARTZ in the Neighborhood." Funded by FFA in 2019-2021, this project is a direct collaboration with members of underserved communities of color in North Philadelphia for the purpose of developing quality-of-life-enhancing programs <u>by</u> <u>and for</u> people living with dementia and their care partners. We are seeking funds to continue the project into Year Four, reshaped but also reinvigorated by the impacts of COVID-19 in the neighborhoods we serve.

#### **Project Details:**

#### Has the problem you have identified changed?

The systemic problems that our project was created to address in 2018 are more pressing than ever. Dementia is still the most pervasive chronic illness in our country: still more dreaded than cancer and as stigmatized as cancer used to be. However, the overlay of COVID-19 has deepened the isolation and alienation from community, friends and family that are the hallmarks of lived experiences around dementia. COVID has hastened the onset and progress of dementia in community members, in part due to the direct impacts of the virus itself but even more broadly due to the months-long periods of quarantine and isolation enforced by its outbreaks and spread. And COVID has only deepened the healthcare inequities that have historically left communities of color at extreme disadvantage when it comes to diagnosing and providing care to those living with dementia.

It is even more evident than when we began this project that the only reliable interventions available to us at this point are those that focus on enhancing quality of life (QoL) -- providing joy and meaning through opportunities for creative self-expression, community-building and dignity preservation. QoL-enhancing programs for people with dementia have historically served predominantly white, middle-to-upper-middle-class constituents. Alzheimer's Disease and other dementias do not discriminate; nor, we believe, should the resources and opportunities intended to combat their devastating impact. People who live in the shadows of dementia within high-risk communities have limited or no access to arts-based or cultural interventions. They are thus without access to experiences that can alleviate isolation or depression, and restore a sense of community. This is truer now, in the age of COVID-19, than ever before.

We aim through our programs to dispel isolation and provide opportunities for participants with dementia to rebuild their self-esteem and their sense of community. With "ARTZ in the Neighborhood," we have embarked on a project that departs significantly from our and others' standard ways of developing programs for people with dementia. We have established a practice

and set of protocols centered on enlisting the end users in creating the programs themselves (with our help), rather than bringing in one-size-fits-all programs forged in other communities with cultural needs and mores that do not speak to the life experiences of those living in the neighborhoods of North Philadelphia.

With the continuing constraints on in-person communication and programming caused by the Delta variant (and others that may follow), we are very purposefully turning our focus in the coming year to alternatives that keep everyone healthy and safe but also build on and honor how our community advisory group members can most comfortably and authentically work with us to expand the reach of the project and its resources.

#### Have your objectives changed?

Our overall objectives for the long duration have not changed: to engage community members with dementia and care partners in interactions around arts and culture who have historically been denied access to such programs; on a larger scale, to develop a consistent practice of seeking direct participation by and mentoring from community members living with dementia in developing resources intended to meet their needs; to set and promote a new standard of community-driven practice in the field for all of us who serve people with dementia; to "manualize" the community-driven best practices that evolve during this project, to disseminate the information and catalyze a policy shift in caring for people living with dementia and their care partners throughout the service sector.

A new set of aspirations and anticipated changes has arisen with the COVID outbreak. Our challenge during 2020 and 2021 has been to achieve similar outputs and outcomes, but through almost exclusively virtual means. In 2022, our objectives are to harness both virtual and (as soon as possible) in-person means to reinforce and expand the positive impacts of the project, building on the lessons we learned during the past two years about the need for communications and programs tailored to individuals' predilections and cultural expectations. Specifically, we plan to work with our community advisors in each neighborhood to bring the resources and opportunities for engagement provided by this project to the faith-based communities within each neighborhood. Faith-based fellowship and connection is fundamental both to the largely Hispanic/Latino population in Hunting Park and the majority African American population in NW Philadelphia. Prior to the pandemic, in February 2020, both of our community liaisons and community advisory groups were getting ready to introduce ARTZ in the Neighborhood in a variety of ways to their church communities. We will be returning to that priority in the coming year.

#### What action(s) will you take to address the changes to problems/objectives?

Our projected actions for Year Four (January – December 2022) reflect the fact that the neighborhoods in which we are working have been changed by COVID. The needs of our stakeholders for strong, safe, supportive community have increased, and their opportunities to find these in person are still compromised and becoming less frequent due to the Delta variant. Our organizational practices have also changed – our official policy is that until the numbers of COVID-related infections have returned to their pre-Delta variant levels, we will be doing very little programming in person. Actions will include:

### Continuing:

- 1. Continuing biweekly community advisory group meetings via Zoom (12 months/yr instead of the 10 months/yr prior to COVID
- 2. Continuing regular check-ins with group members between regular meetings, via text, phone, mail.
- 3. Continuing to address technology needs of community members related to full engagement with and participation in the project.
- 4. Continuing to develop online and in-person community-led programs piloted during 2020 and 2021

#### New:

- 1. New efforts to introduce the project to faith communities within each neighborhood through connections facilitated by community advisory group members
- 2. Resuming regular "Café for Carers" programs (online and in person when possible) in NW Philadelphia, created and facilitated by our community liaison there; and Café para Dos programs in Hunting Park
- 3. Arts-based initiatives (continuing and new):
  - a. Continuing co-creation of "community conversations"/adult coloring book modeled on the Hunting Park "flip book" created in 2018 and 2019; themes to include food, music, poetry, visual art; community members' stories (as in flip book) as the scaffolding; reflections on the impacts of COVID-19 on neighborhoods (a special component prioritized by community members) and illustrations of community members engaged in activities relevant to themes, by community artist Raquel Algarin (funded by FFA in 2021. This work has been carried out exclusively online during 2021 and has experienced substantial delays as a result. Our hope is that this project and the mural project (b) will progress in tandem and inform each other's imagery and stories.
  - b. Partnership with Mural Arts Philadelphia, continued from 2021. Delays resulting from challenges in communications among Mural Arts, ARTZ, and Esperanza Health Center and other community members have necessitated extending the project into 2022. (Please see progress report for 2021.)
  - c. Community advisory group members and their networks will recommend and vet musicians for the 3<sup>rd</sup> year of the ARTZ Notes music-based program (which has been exclusively online through 2022) and "Music in the Neighborhood," an interactive music program launched in July 2021 and continuing through June 2022. July, August, and September 2021 programs have been in-person.
  - d. Still to be defined: collaboration with Esperanza Arts Center, the Philadelphia region's premier center for Latino arts and culture, located just a few blocks from Esperanza Health Center (the two are not related except in the communities they serve).

## What will success look like?

Success will entail the following outcomes:

"Deliverables":

- Completion of community mural at 6<sup>th</sup> and Cayuga Streets in Hunting Park, *engaging 20-30 people*
- 2. Completion of community conversation book, *engaging 10-20 people in co-creation and an additional 40-60 people through dissemination*
- **3.** Delivery of monthly "Music in the Neighborhood" music programs online, outdoors in Hunting Park or in NW Philadelphia, *engaging 100-200 people*
- 4. Delivery of periodic bilingual ARTZ Notes music programs online or at venues near or in Hunting Park or NW Philadelphia, *engaging 50-60 people*
- 5. Partnership project co-planned, co-designed, co-created with community members and Esperanza Arts Center, *engaging 30-50 people directly (?)*
- 6. Continuation of bi-monthly FaceBook Live programs (*reaching on average 100 people per program*) and posts and discussions on "Life After Dementia" FB page, *reaching additional 150 regular viewers beyond the current 140*

"Impacts":

- 1. Community members with experiences of the stigmas and isolation of living with dementia continue to articulate increased hope and restored sense of community through participating in the project.
- 2. Community members with dementia and care partners continue to feel "heard" by their community, some for the first time, others, in new ways.
- 3. Community members with dementia and care partners experience a new sense of selfdetermination and dignity through participating in a project whose mission is to hear, understand, and meet their needs in various ways.
- 4. Community members gain sense of self-esteem, empowerment and connection by encouraging and attending to each other's stories around dementia and taking on the responsibility for making such connections.
- 5. The compounded sense of isolation and alienation resulting from the impacts of COVID-19 on people living with dementia and their families will be measurably lessened and QoL increased by both online and in-person programs (the latter if and when possible).

## Project budget, including other sources of support, budget narrative.

## **Budget Narrative:**

# The total budget for this project in 2022 will be \$85,700.

ARTZ Philadelphia Executive Director will serve as the project director for this grant. Her annual salary is expected to be \$58,000 in 2021; she will spend 25% of full time on this project. ARTZ Philadelphia's Community Engagement Coordinator will continue to serve as the

primary staff person for this project. Her annual salary is expected to be \$51,000 in 2021; she will spend 50% of full time on this project. Technical support, photography, and video documentation will be provided by our Digital Projects and Program Manager at 20% of full-time, annual salary expected to be \$51,000. Community liaisons (2) will each be paid \$7,500. The contract project evaluator will receive a reduced project fee of \$8,000 for the year. As discussed in our progress report for 2021, due to the challenges related to conducting focus group interviews and data gathering experienced by our project evaluator during the pandemic, we have added a new paid project position to assist in those areas, with a stipend of \$2000-\$3000 attached to it. The job description for that new research assistant position is as follows:

**Job Description**: Seeking a current or recent graduate student(s) in anthropology, education, sociology, public health (a combination of the aforementioned is welcome), or a related field for a research assistantship position. Some experience with qualitative research (e.g. semi-structured interview; fieldnotes) and/or graduate work in anthropology/ethnography/phenomenology is a requirement. This position begins in 2022 and requires some travel. Pay is \$15/hour.

ARTZ Philadelphia and Mural Arts will continue to cost-share the fees for the mural artist on our collaborative project (*funds carried over from 2021 as necessary*). The fees for our ARTZ Notes lead program facilitator (responsible for overseeing the program administratively and its creative driver) will be cost-shared 30/70 between this project and our operating budget. ARTZ Philadelphia and Esperanza Arts Center will cost-share the planning and development of a new partnership project for 2022-2023.

# **Provisional Sources of Additional Financial Support for Project and General Operating Support:**

Acadia Pharmaceutical, Inc., \$5,000 in hand (program); Janssen Pharmaceutical, Inc, \$7,500 pending (project); Lawrence Saunders Fund, \$3000, pending (program); Connelly Foundation, \$10,000 pending (gen ops); Fox Chase Bank Charitable Fund, \$5000 (gen ops); Patricia Kind Family Foundation, \$15,000 pending (gen ops); Henrietta Tower Wurts Memorial/The Philadelphia Foundation, \$5,000 pending (gen ops); dedicated individual donations in hand: \$3,500.