

OCMH Grantee Abstracts

Lupus Grantees

Grantee Agency: Lupus Foundation of America, Greater Ohio Chapter, Inc.

Project Title: Helping Solve the Cruel Mystery of Lupus

The Lupus Foundation of America, Greater Ohio Chapter, Inc. was formed in 1977 by patients, their family members and friends whose lives were affected by the consequences of this terrible illness. At that time, there was little known about lupus and most of the information was inaccurate. A need was recognized and the Lupus Foundation of America, Greater Ohio Chapter, Inc. (LFA, GOC) was born. The LFA, GOC aspires to reach every individual with lupus in our service area with the support, services and hope that they need. We know that until there is a cure, we are a vital resource for lupus patients and their families. It is essential that we continue to foster relationships with those we serve. Ultimately the LFA, GOC leads patients towards a better journey with their lupus. Our support helps lupus patients to accept their illness and empowers them to lead a better quality of life: one that is lived to its fullest and most meaningful potential. The LFA, GOC is a critical navigator of the lupus patient's journey. Our targeted population is anyone and everyone affected by lupus. This includes patients and caregivers, friends and family.

The LFA, GOC provides support groups, educational programs, gatherings and events for lupus patients and caregivers. We host three commission funded support groups monthly as well as one lupus educational summit and one lupus gathering.

We have an excellent marketing team that helps to promote all of our events via Facebook, Instagram, Twitter, and Pinterest, as well as our website and press releases. We also create direct mail pieces that are distributed to our many constituents that advertise our support groups, new patient education classes, events and educational programs.

We will measure outcomes by way of sign in sheets and demographic forms. All people who attend will remain anonymous.

Overall, our main goal is to accomplish our mission of improving the quality of life for all people affected by lupus through programs of research, education, and advocacy. We do this by providing as much support and education to lupus patients and their families and friends as possible. The patient is at the heart of our organization and the sole reason we exist. We are here to help them navigate through their journey with lupus.

Grantee Agency: Lorain Urban Minority Alcoholism and Drug Abuse Outreach Program

Project Title: Where R U?

The Lorain Urban Minority Alcoholism and Drug Abuse Outreach Program Inc. (UMADAOP), is a 501 c (3) organization, serving residents in Lorain, Ohio and surrounding Counties. *Lorain UMADAOP has worked to improve the quality of life for Lorain County residents by providing services that build self-reliance and foster personal and education achievement, since 1991.* The agency is well known and trusted in the community as a beacon of **“Hope”** for the people who need assistance with a variety of concerns and/or services.

The agency is proposing to provide information on lupus to Lorain County residents/community. The project entitled **“Where R U”?** The agency has been a provider for the past two years and has found a niche working with individuals who have lupus. The program will reflect the target populations attitudes, values, and beliefs as it implements the program activities. Program outreach will target minority women in the community. It has been our experience that individuals with lupus are very private, however, they will participate in support groups when they can identify with someone else who has lupus. The program will recruit seven additional individuals who have lupus and ten caregivers and/or family members to participate in the support groups and activities.

Grantee Agency: Ross County Community Action, Inc.

Project Title: Learning to Live, Cope, and Survive with Lupus

The primary component of our proposal is to continue to expand all components of the successful program that has been established for the first time in our area with funding from the Ohio Commission on Minority Health. This includes continuing and expanding efforts in the areas of Outreach and Awareness, Access to Lupus-Related Services, and Optimum Health Group Effectiveness.

Grantee Agency Name: Steubenville Health Department

Project Title: Lupus Optimum Health

Lupus Optimum Health is a program to provide support, education and outreach to those in the Steubenville/Jefferson county area who have been diagnosed or know someone diagnosed with lupus. The focus groups are attended regularly by an average of twelve-fifteen individuals and this meeting exhibits the positive aspects of our community. The support group gives family members, caregivers, and patients the opportunity to talk with each other in a private setting. The meetings are held monthly on the first Monday of the month. Goals for the program is do proactive community outreach to get the community involved in the Lupus Optimum Health activities, to spread education on the health condition to the community, and to engage our local community partners.

To increase the awareness and education of Lupus in the Jefferson County area. Through diverse educational support groups, activities, and community outreach with the assistance of community partners.

Grantee Agency: Nuestra Gente Community Projects, Inc.

Project Title: Minority Lupus Program

We expect our support groups to provide an oasis for persons suffering with lupus. People with this chronic disease often feel lonely and depressed and are

anxious about what is happening to them. The physical burdens and special fears that all patients and their families experience need to be addressed.

Support groups provide a wonderful and nurturing environment for people living with lupus and their families. They receive accurate knowledge from professionals, which will help them better understand their role in controlling the disease. We expect support group participants to be able to lead normal lives from this program. If participants utilize the knowledge obtained in meetings it will help them prevent or lessen the number of lupus flare-ups. Participants will develop friendships within the group and realize that they are not alone and understand that their disease can be managed and life is worth living.

Grantee Agency: William E. Sanders Family Life Center

Project Title: WESFLC Optimal Lupus Health Group

The WESFLC Optimal Lupus Health Group's mission is to increase the community awareness of this disease by providing education, resources, comfort, encouragement, and friendship for those diagnosed with lupus, their family and friends. Young minority women are at a higher risk for lupus, suffer more life-threatening complications and are most likely to be diagnosed at a younger age than white women. Young minority women are also the most difficult to recruit and the challenge is to find a method that will convince these young adults that the education and support from this group will be beneficial. For this grant period we are planning to conduct a seminar, "Do You Have Lupus?" This program will be used as continuing education for people living with lupus, their family, friends and caregivers.