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Advocacy News

Arthritis Foundation, Inc., New York Chapter • 122 East 42nd Street • New York, New York 10168-1898 • (212) 984-8700

New York City Council Partnership A Long History of Success

Once again, the New York Chapter is thrilled to announce the recent allocation of \$56,250 from the New York City Council. In these difficult economic times, this funding is critical to ensure that the Chapter continues to provide evidence-based disease management programs and educational forums to a growing number of New Yorkers living with arthritis. Now in its eighth year, the New York City Capacity Building Partnership has proven to be extremely successful in reaching diverse and underserved populations throughout the city. Thanks to the efforts of Council Speaker Christine C. Quinn and Council Members Maria del Carmen Arroyo, Alan J. Gerson and David Weprin, the Chapter will be able to further expand our reach.

The Chapter's partnership with the New York City Council began in 2002 with a grant awarded for the implementation of the *Arthritis Foundation Exercise Program* (known at the time as *People with Arthritis Can Exercise*) in various community sites located in the first district of lower Manhattan. Council Member Alan Gerson championed these efforts. As word spread of the remarkable impact that these classes had on participants, other districts became interested in holding the program. In the grant years that followed, the Chapter first expanded the city partnership into the third district in Manhattan and later into Brooklyn, Queens and the Bronx. In addition to increasing reach, the Chapter also diversified its efforts by offering additional disease management programs to city sites, including the *Arthritis Foundation Aquatic Program*, the *Arthritis Foundation Self Help Program* and the *Arthritis Foundation Tai Chi Program*. Public education forums, which serve to educate the public about key topics in the diagnosis, treatment and prevention of arthritis, were also included in the partnership. **In total, the Chapter has received over \$300,000 in funding and reached over 3,900 New Yorkers through this longstanding collaboration.**

Each year, statistically analyzed pre and post course questionnaires have illustrated the beneficial impact of the Chapter's evidence-based disease management programs. This year has once again proven to be a success. Results from class participants indicate vast improvements in pain

management and mood, increased confidence in symptom management and a clear understanding of the benefits of exercise. As in previous years, participants were extremely satisfied with the courses and stated that they intend to make key lifestyle changes as a result of course participation.

Action Alert

The following New York City Council members have been instrumental in securing funding for the Chapter's *New York City Capacity Building Partnership*. The Chapter is especially grateful to these individuals. Please take time to thank them for their efforts and allowing the Chapter to continue providing beneficial services to New Yorkers living with arthritis.



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If there are currently no arthritis disease management programs or forums in your neighborhood, contact your local council member and request that these services be offered in your area.

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Update on Health Care Reform

With health care reform at the top of the agenda in Washington, the Arthritis Foundation proposes the following principles be included in any pending legislation:

1. Universal Access to Efficient Health Care for People with Arthritis

- a. Guarantee comprehensive, essential health care benefits for all.
- b. Eliminate pre-existing condition exclusions.
- c. Ensure that coverage is continuous and portable.
- d. Remove the 24-month waiting period for Medicare coverage.
- e. Ensure the physician and allied professional workforce is adequate to reach people with arthritis in underserved communities.
- f. Identify factors contributing to health care disparities and develop solutions to remedy them.

2. Affordable, Sustainable, Comprehensive Care for All

- a. Ensure insurance premiums are reasonable and affordable to patients with chronic diseases.
- b. Set reasonable co-payments for medications, specifically biologics for rheumatoid and juvenile arthritis patients.
- c. Prohibit sale of insurance plans that provide no prescription drug coverage.

3. Preventive, Quality Care for All

- a. Increase and foster early and sustained access to coordinated, preventive care for patients with arthritis.
- b. Increase early access to evidence-based interventions.

4. Health Information Technology to Increase Efficiency, Improve Health Outcomes and Facilitate Coordination of Care

- a. Incentivize the use of information technologies to conduct epidemiological studies, monitor the long-term effects of therapies and interventions and coordinate care amongst multiple providers.

5. Comparative Effectiveness Research (CER) to Improve Outcomes and Reduce Costs

- a. Establish a framework for evidence-based comparative effectiveness data to provide clinical decision support to providers and people with arthritis.

The FDA Questions Side Effects of TNF Blockers for Children

The Food and Drug Administration (FDA) is requiring the manufacturers of tumor necrosis factor (TNF) blockers to update the boxed warning and prescribing information to alert health care professionals of an increased risk of malignancies in pediatric patients treated with TNF blockers. The FDA's safety review and analysis is based on 48 cases of malignancies – including lymphoma and other cancers – in children and adolescents treated with TNF inhibitors. This is an ongoing investigation by the FDA, and the Arthritis Foundation expects more information from the FDA in the future.

TNF blockers, also known as biologic response modifiers, are approved for the treatment of one or more immune system diseases, including juvenile idiopathic arthritis (JIA, formerly known as juvenile rheumatoid arthritis, or JRA), rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and Crohn's disease.

TNF therapies are improving the lives of millions of Americans and they are important treatment options for people with inflammatory forms of arthritis, such as JIA. The Arthritis Foundation concurs that additional data and further analysis are needed, however, to determine whether malignancies are a direct result of TNF blocker use or whether they are related to other risk factors associated with arthritis.

The Arthritis Foundation believes the FDA's decision will help to inform healthcare professionals and their patients about the potential risks associated with this class of drugs. If there is an increased risk of cancer in JIA patients treated with TNF blockers, it appears to be small, particularly when compared to the risk of disability from untreated juvenile arthritis.

Therefore, the Arthritis Foundation urges adult patients and parents of children being treated with TNF blockers to:

- **consult their prescribing physician to discuss their individual situation before altering treatment or taking any action on their own;**
- **work closely with their physicians to understand risks and benefits clearly before choosing a treatment plan; and**
- **be alert to the warning signs and symptoms of malignancies, and undergo cancer screenings appropriate for their age and gender.**

The concern about adverse side effects with TNF blockers further emphasizes the need for a national registry for patients with JIA as well as a network of collaborating treatment centers to ensure that full information can be acquired about the risks and benefits of arthritis therapies. The Arthritis Foundation is working toward this goal through its support for the Childhood Arthritis & Rheumatology Research Alliance (CARRA). CARRA is a North American organization of pediatric rheumatologists who have joined together to answer critical clinical research questions and determine the best possible treatment options for childhood arthritis and other childhood rheumatic diseases.

For more information about arthritis and treatment options, visit the Arthritis Foundation Web site at www.arthritis.org.