

The New York Arthritis Reporter

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



If your child has JRA...

Pain, swelling, and stiffness in joints that have persisted for at least six weeks... irritability, fever, rash...these are signs that your child may be among the estimated 1 in 1,000 children nationwide who have an immune system disorder known as juvenile rheumatoid arthritis (JRA), also called juvenile idiopathic arthritis (JIA) and juvenile chronic arthritis. **How quickly a correct diagnosis is made, and the quality of subsequent healthcare, will have a significant impact on the disease's prognosis and on your child's ability to lead a full and productive life into adulthood.**

"Often a diagnosis is delayed because physicians don't readily recognize the symptoms as JRA, and joint damage has already been allowed to occur," says Dr. Norman T. Ilowite, Chief, Division of Rheumatology, Children's Hospital at Montefiore. "For the best outcomes, it is imperative that you locate a pediatric rheumatology center with experienced specialists in the fields of

physical/occupational therapy, orthopedics and ophthalmology. As a parent, your best ammunition in navigating your child through treatment options and the emotional and social issues which may arise is keeping informed."

Medication dosage for children is based on weight and metabolism and will most likely be adjusted as the treatment progresses. **The important treatment objectives are to try to reduce pain, get the child's disease in remission, and prevent joint damage, thus permitting normal growth and development.**

"As we learn more about JRA and the joint damage that can develop relatively early, pediatric rheumatologists are treating patients more aggressively to reduce pain and prevent joint destruction which results in better functional outcomes. This is especially true of children diagnosed with polyarticular JRA (five or more joints), as these children tend to predictively have more problems in the long run," Dr. Ilowite said.

Depending on the severity of the disease, the first line of treatment for polyarticular JRA is methotrexate, which belongs to a group of drugs known as DMARDs (disease-modifying anti-rheumatic drugs). These drugs work on the immune system to retard joint destruction and reduce inflammation. For some patients, improvement is noted within weeks, while others may not respond to treatment for months. If your child is on methotrexate, signs of nausea, fatigue, mouth sores or abdominal

pain may indicate that the medication needs to be changed or adjusted. Dr. Ilowite explains that "if a child doesn't respond to methotrexate, the next course of action is to either add or substitute one of the biologic drugs (treatments which target specific agents within the immune system known to cause inflammation)." Signs of infection or unusual behavior in children taking biologics should also be reported to your physician. While data shows good evidence of the effectiveness and safety of biologics for children over the short-term (up to eight years of treatment), there is no conclusive data that these medications are safe in the long run. The risks associated with these treatments, however, are deemed worth the benefits of treatment in children with an inadequate response to methotrexate.



(Continued on page 2)

State Expansion Proposal Up for Renewal

The New York Chapter is proud to announce that the New York State 2007/2008 Executive Budget includes a proposed allocation of \$250,000 to expand arthritis disease management programs for New Yorkers. We thank **Governor Eliot Spitzer** and his administration for their commitment to help us continue our mission to serve more New Yorkers with arthritis; and we encourage the New York State Senate and Assembly to support this Executive proposal to continue the expansion of arthritis disease management services statewide.

Documented health outcomes studies conducted by an evaluation team at the State University of New York at Albany attest to the effectiveness of our disease management and exercise programs in improving general health, pain management, changes in arthritis symptoms, self-efficacy attitudes and beliefs about abilities to exercise and manage symptoms among individuals with arthritis. With state support over the past five years, the four New York State chapters of the Arthritis Foundation have reached a total of nearly 11,000 people and have trained a group of 1,000 instructors.

This issue is underwritten by an educational grant from Wyeth.

THE 6TH ANNUAL

Kids get Arthritis, Too



Family Day

Saturday, June 16, 2007

9 a.m. to 3 p.m.

Burke Rehabilitation Hospital
White Plains, NY

Join the Chapter and sponsors **Wyeth** and **The Louis R. Cappelli Foundation, Inc.** for a fun-filled day of indoor and outdoor activities and informative, interactive sessions for parents, teens and children. (Breakfast and lunch are included.)

Program features:

Arthritis & the Family
Exercise & Physical Therapy

New Treatments
School Issues

Nutrition & Herbal Basics

For more information, call the Chapter at (212) 984-8730.

If your child has JRA (continued from page 1)

"Children with pauciarticular JRA (four joints or less) respond well to intra-articular injections of long-acting corticosteroids. This form of treatment is being used more and more often to prevent long-term exposure to non-steroidal anti-inflammatory drugs (NSAIDs) which have been found to be associated with cardiovascular toxicity in adults. One side effect of NSAIDs, especially naproxen, seen most commonly in young children who are fair-skinned, is a scarring rash of the face and other sun-exposed areas. Children with pauciarticular JRA, however, often have a better chance of outgrowing JRA than their polyarticular counterparts," Dr. Ilowite explained.

Children with JRA, especially young patients with pauciarticular or polyarticular disease who also have a positive ANA (blood test), are more likely to develop a serious inflammatory eye disease, uveitis, and frequent ophthalmic check-ups are necessary.

If a patient with JRA experiences a complete remission, physicians usually continue the medication for at least 6 months to a year before seeing how the child can do without it. The challenge for parents of children with arthritis is to encourage adherence to prescribed treatment (even when the child is in remission) while not making the child feel (emotionally, socially and physically) different from other members of the family and peers.

For more information on JRA, go to www.arthritis.org, click on "Conditions and Treatments," then "Juvenile Arthritis;" or call the **New York Arthritis Exchange™** telephone helpline, sponsored by Pfizer Inc, at 212.984.8730, or, from the 914 or 845 area codes only, 800.246.2884.

Advocacy Update



New Momentum for Arthritis Bill in Senate

On February 15 Senator Kennedy introduced the *Arthritis Prevention, Control and Cure Act* (S.626) in the Senate, with Senators Bond (MO), Akaka (HI), Leahy (VT), Menendez (NJ), Craig (ID), and Shelby (AL) joining him as original cosponsors.

This is great news for the Arthritis Foundation and people with arthritis. Senator Kennedy is now the chair of the Senate Health, Education, Labor and Pensions Committee, the committee of jurisdiction for the bill; and having his support for this legislation is a major coup.

The Arthritis Foundation worked closely with staff members of Senators Kennedy and Bond to prepare an updated version of the legislation and is also working closely with sponsors in the House where it is anticipated that companion legislation will soon be introduced.

The *Arthritis Prevention, Control and Cure Act* expands the federal government's efforts to prevent, treat and find a cure for arthritis. It focuses on three primary areas: (1) investing in a public health initiative to reduce the pain and disability of arthritis through early diagnosis and treatment, (2) addressing the nationwide shortage of pediatric rheumatologists, and (3) forming an Arthritis Interagency Coordinating Committee to improve efficiency among federal agencies cooperating in arthritis research and public health activities.

Free Program for Kids with Arthritis and Parents at Chelsea Piers

Please join the New York Chapter of the Arthritis Foundation for **An Afternoon at Chelsea Piers** on **Sunday, March 25** at **The Field House at Chelsea Piers – Pier 62, 23rd Street and Hudson River Park, Manhattan.**



Thanks to the generous support of New York State, children with arthritis between the ages of 5 and 16 are invited to enjoy an action-packed afternoon of age-appropriate activities under the supervision of specially-trained Chelsea Piers instructors. At the same time, parents will get an update from health specialists on the latest in research advances and treatments, exercise and nutrition guidelines for their children with arthritis. Parent workshops will be conducted by **Patricia I. Irigoyen, MD**, Pediatric Rheumatologist, Children's Hospital Montefiore, and **Sotiria Tzakas, RD**, Pediatric Nutritionist, Hospital for Special Surgery. The schedule for the afternoon is as follows:

2:00 – 4:00 p.m.

Activities for kids with arthritis
Parent workshops

4:00 – 5:00 p.m.

Pizza party

While the program is **free**, pre-registration is required. Please call the Chapter at (212) 984-8730 for more information or to register.

NEW YORK CHAPTER



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www.arthritis.org

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Copies of our financial and operating report have been filed with the state and are available upon request. To obtain one, write: Office of the Attorney General, Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271, or contact us at the address above.

Questions and Answers

Philip J. Kahn, MD is Clinical Assistant Professor of Pediatrics at the Morgan Stanley Children's Hospital of New York-Columbia Presbyterian

Q: What has been your experience with exercise issues for children with arthritis?

A: As a general observation, children will limit their exercise when it hurts. As a doctor, I never advocate restricting physical activity for children with arthritis provided it falls within the parameters of what they can do, i.e., it is an activity within their comfort range, and it will not promote injury or additional joint problems. Children with contractures or other deformities may have to modify the activity, but certainly, participating at some level, say in gym class or in a sport, is preferable to sitting on the sidelines and being stigmatized.

It is important to **focus on what the child can do** and build physical activity around that. For instance, if a child's fingers are painful and stiff, encourage calisthenics or swimming instead of ball games.

Of course, it is a great benefit if children would adhere to a regular program of range of motion and strength building exercises, as these will help prevent stiffening and deformity. A physical or occupational therapist can develop and demonstrate an appropriate exercise regimen on an individual basis; and parents should encourage children to make these exercises part of their at-home routine.

For children who complain about not having enough time for exercise, or that equipment or gym membership is expensive, I often recommend jumping rope while watching a favorite television program. A jump rope is inexpensive, requires a minimum amount of space, and a child can gradually increase the time spent jumping to gauge progress. This can easily be done regularly -- every day, or three or four times a week for the best results.

Q: Are there any special nutritional guidelines for children with arthritis?

A: There are no specific food groups recognized as beneficial for children with arthritis, but as is true of anyone, a well-balanced diet is certainly an advantage for overall well-being. While a small percentage of children with severe systemic JRA may suffer

loss of appetite, the more common situation is that children come to me with poor eating habits and they need to reduce their calorie intake, especially if they gain weight as a side effect of medication such as prednisone.

If it is difficult for an adult to adhere to a diet with a prescribed amount of daily calorie, protein and carbohydrate intake, how much more difficult is it for a child! My approach is to simplify the process. I examine the eating habits of the patient and select one thing that would have a positive impact on the diet. For

instance, if I notice that the child consumes four or five sugary soft drinks a day, I suggest switching over to water or some other beverage that is less caloric. If the problem is an excess of fatty foods, I recommend trying baked or grilled food instead, or introducing new vegetables or more fruit into everyday meal planning.

Often, that one diet adjustment may involve a lifestyle change for the entire family, but it is not as overwhelming to children as strict adherence to a prescribed diet and is therefore within reach of most pediatric patients and could only be a step in the right direction for the whole family.

For exercise and diet tips for children with arthritis, please visit www.arthritis.org or call the **New York Arthritis Exchange™** telephone helpline, sponsored by Pfizer Inc, at 212-984-8730, or, from the 914 or 845 area codes only, 800-246-2884. Request a copy of the free brochure, *Arthritis in Children*, or order a copy of the Arthritis Foundation publication, **Raising a Child with Arthritis, A Parent's Guide** (\$14.95).



Visit Our Thrift Shop

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1383 Third Avenue • New York, NY 10021
(212) 772-8816

Donations always welcome.

FREE Arthritis Foundation Self-Help, Osteoporosis and You, and Arthritis Foundation Exercise Programs for GHI Subscribers

Pre-registration required, contact Wendy Isaacs at (212) 984-8713 for locations in our Chapter region.

Celebrating Brooklyn's Leaders – May 4th

The New York Chapter of the Arthritis Foundation will host its 18th Annual **Brooklyn Leaders' Award Luncheon** on Friday, May 4th at the Brooklyn Botanic Garden Palm House. The luncheon provides a forum for the Chapter to celebrate the borough's business, community, and physician leaders who have helped improve the quality of life for people with arthritis in Brooklyn. The event also helps raise funds to provide Brooklyn residents with educational and disease management programs and information about arthritis while supporting research into the disease's cause, treatment and prevention.

This year's luncheon will honor:

Martin Valdes, M.D., M.B.A.

Chief Executive Officer, Central Brooklyn Medical Group

Dominic R. Mascara

Managing Partner, Mosaic Business Group, LLC

Jitendra K. Patel, M.D.

Chief of Rheumatology, Kingsbrook Jewish Medical

For more information, call Mattie Shephard at 212-984-8706.



New York Chapter is BBB Seal Holder

The New York Chapter is a proud holder of the Better Business Bureau of Metropolitan New York Charity Seal. Of the 60,000 charities registered within New York State, only a little more than 300 meet the 20 standards established by the Better Business Bureau. Of those 300 charities, only a third currently participate in this watchdog group's Charity Seal Program. For additional information about the BBB program, please go to www.newyork.bbb.org.

Mifa Rogoff remembered the Chapter in her will with a bequest of \$1,000.

A distribution of \$10,000 from the estate of Pamela B. Schapper will support programs for people with arthritis.

The estate of Robert S. Steeger, Sr. provided the Chapter with a distribution of \$10,000 which will support patient services for people with arthritis.

The October Fund

A Family Reaching Out



Wendy Goldstein

The brightly colored leaves on the trees and the invigorating October chill in the air could not comfort the Goldstein family when daughter, Lindsay, was diagnosed with juvenile rheumatoid arthritis. "October brought with it a sense of sadness for our family because it was the anniversary of the acute onset of Lindsay's rheumatoid arthritis," recalls Lindsay's mother, Wendy. "After the diagnosis, we started going to arthritis support groups and met other children and families who didn't have the resources we had in dealing with this illness. As bad as it was for us, it was far worse for many of them," she said.

The Goldsteins wanted to do something to help those children they met. And they wanted to change the rhythm of sadness in their family that October brought with it. So they came upon the idea of starting a fund that would help children with arthritis engage in recreational activities that the added expense of a chronic illness kept out of reach for many of them and their families.

Now, a decade later, the Goldstein family, through the **October Fund**, has raised more than \$500,000 and has helped 240 children with arthritis fulfill their dreams. Wendy says that "seeing the happy and confident faces of those children in the photos they send us and reading their letters are very gratifying experiences which have helped us all see October in a brighter light."

Recognized by the American Juvenile Arthritis Organization (AJAO) with two National Awards of Excellence, the **October Fund** continues to provide the opportunity for children in the region to forget their arthritis and enjoy the fun things about being a kid. For information on how your child can take advantage of this opportunity, please call the Chapter at (212) 984-8712.

Dates to Remember

Hospital for Special Surgery

535 East 70th Street, 2nd Floor, New York, NY

April 24 Bone Health for Your Spine

5:30 PM - 6:30 PM

May 8 Current Treatment in RA:

Which One is Right for You?

5:30 PM - 6:30 PM

Metro SportsMed Physical Therapy

380 Second Avenue @ East 22nd Street, New York, NY

April 25 Shoulder Bursitis:

Causes & Treatment Options

Noon - 1:00 PM

May 18 Lower Back Pain and Arthritis

Noon - 1:00 PM

Poughkeepsie Galleria

790 South Road, Poughkeepsie, NY

April 12, May 10

Arthritis Support Group

1:00 PM - 2:00 PM

Physical Therapy at Briarcliff

584 North State Road, Briarcliff Manor, NY

April 4, May 2

Chronic Pain/Fibromyalgia Support Group

1:00 PM - 2:00 PM

Programs require pre-registration. For further information, call the **New York Arthritis Exchange™** at (212) 984-8730 or, from the 914 and 845 area codes only, 800-246-2884.

Get Fit, Take Control

Take Control With Exercise DVD

(\$19.95) is an upbeat 60-minute DVD which provides a balanced exercise routine based on the Arthritis Foundation Exercise Program. The DVD includes two optional endurance routines to create a more challenging workout and a relaxing guided imagery segment to help you manage stress.

To order, please call the **New York Arthritis Exchange™** telephone helpline at 212-984-8730, or, from the 914 or 845 area codes only, 800-246-2884.



A distribution of \$74,574 from the Ilse G. Coe Trust will support arthritis research.

Visit the Features on our Web site

- Arthritis Advocates in Action
- Advocacy News
- Your Direct Access
- Kids Get Arthritis, Too
- Food for Thought
- The New York Arthritis Reporter
- Información en español



Log on to www.arthritis.org. Enter your zip code to find the New York Chapter.

New Guides Available

We are pleased to announce that the Foundation has developed some new materials to keep you informed on the latest in arthritis treatments.

- The **2007 Drug Guide**, which appeared in the January-February issue of **Arthritis Today**, is a free, comprehensive reference to help people make informed decisions in dealing with the pain of arthritis.
- A newly updated **Essential Guide to Arthritis Medications** (\$9.95) features an A-to-Z listing of more than 250 medications for people with arthritis and related diseases, including the latest biologic drugs to be approved this year.

To order, please call the **New York Arthritis Exchange™** telephone helpline at 212-984-8730, or, from the 914 or 845 area codes only, 800-246-2884.

Emma Katenkamp remembered the Chapter in her will with a bequest of \$1,000.

The Chapter is grateful for a distribution of \$1,000 from the estate of Martha Katenkamp.

The estate of Belle R. Schlossberg provided the Chapter with a distribution of \$3,500.

A bequest to the Chapter of \$1,000 was thoughtfully made by Esther Kahn.

In the Next Issue: Exercise