

The New York Arthritis Reporter

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



The Centers for Disease Control and Prevention estimate that 294,000 U.S. children under age 18 (approximately 1 in 250 children) have been diagnosed with juvenile arthritis (JA) or another rheumatologic condition. However, despite these statistics, many people still think of arthritis as an adult condition. "This misconception is one of the key challenges in ensuring that a child with arthritis receives a prompt and early diagnosis," says Dr. Beth Gottlieb, Chief of Pediatric Rheumatology at Schneider Children's Hospital in Queens. "Many parents assume that their child's swollen joint is the result of an injury or trauma, but too often this is not the case."

Even when parents do recognize their child's symptoms as a potential sign of arthritis and visit a pediatric rheumatologist, diagnosis can be a difficult and lengthy process. Often called a diagnosis of exclusion, physicians must

Growing Up With Arthritis

first be sure to rule out any other disease that may mimic arthritis or be related to joint pain and swelling. This process includes recording a child's complete health history, administering a full physical examination, and running any necessary laboratory or screening tests. In addition, a child must have arthritis in one or more joints for at least six weeks to receive a diagnosis of juvenile arthritis.

Children can be diagnosed with a variety of different types of arthritis. JA, an umbrella term, includes:

- Polyarticular Juvenile Rheumatoid Arthritis (JRA) or Juvenile Idiopathic Arthritis (JIA) which affects five or more joints
- Pauciarticular JRA or JIA, which affects four or fewer joints
- Systemic onset JRA or JIA, which includes a high fever and a characteristic rash
- Other rheumatologic conditions such as: Spondyloarthritis, Psoriatic Arthritis and Inflammatory Bowel Disease.

"Although receiving a diagnosis can be a difficult process, it is a critical piece of the treatment puzzle," Dr. Gottlieb explains. "The good news is that once a child has been accurately diagnosed, there are now many effective treatment options that, if administered correctly and monitored by a physician, can prevent long-lasting joint damage, minimize pain and allow a child to lead a normal, healthy life."

The goals of any treatment program for a child with JA include: controlling inflammation, relieving pain, preventing further joint damage and maximizing his/her ability to participate in

everyday activities. Since there are a variety of treatments, it often takes a team of health care providers, who are working together, to provide the best possible treatment. Dr. Gottlieb explains, "This 'circle of care' should not only include the child and his or her parents, but must also include the child's pediatrician, pediatric rheumatologist, and ophthalmologist (some forms of JA can result in eye inflammation). It may also include a physical therapist, a social worker and members of the child's school faculty." By



involving professionals from different fields, you can be sure that your child is receiving the necessary care.

The first line of treatment for any form of JA are nonsteroidal anti-inflammatory drugs such as ibuprofen or naproxen. After that, if necessary, physicians may administer corticosteroids (usually injected directly into the inflamed joint). Other treatments include disease-modifying anti-inflammatory drugs such as methotrexate and biologic response modifiers such as etanercept and

(Continued on page 2)

EmblemHealth Renews Partnership!

The Chapter is pleased to announce our renewed partnership with **EmblemHealth**. After a long-standing relationship with Group Health Incorporated (GHI) and HIP Health Plan of New York (HIP), the two healthcare delivery systems that merged to create EmblemHealth, this collaboration continues to provide subscribers with access to our free evidence-based disease management programs. Classes include: *The Arthritis Foundation Exercise Program*, *The Arthritis Foundation Self Help Program* and *The Arthritis Foundation Tai Chi Program*.

During the past ten years, the Chapter has provided over 400 courses and reached more than 11,000 subscribers through our partnerships with HIP, GHI and now, **EmblemHealth**.

This issue is underwritten by an educational grant from Wyeth.

Meet Our JA Fellows

The Chapter is pleased to promote the professional development of pediatric rheumatologists through our comprehensive fellowship program. As the country faces a national shortage of pediatric rheumatologists, supportive efforts such as these fellowships are key to encouraging new findings in the diagnosis and treatment of juvenile arthritis (JA). This year, the Chapter is sponsoring two pediatric fellows: **Kabita Nanda, MD**, of Schneider Children's Hospital who has been awarded the *JRA Heroes Fellowship Award in JA* and **Cagri Yildirim Toruner, MD** of New York Presbyterian Hospital/Columbia University Medical Center who is the recipient of the *Charles and Mildred Schnurmacher Foundation Fellowship Award in JA*.



Cagri Yildirim Toruner, MD



Kabita Nanda, MD

Dr. Nanda is studying the impact of race on the different subtypes of JA (polyarticular, pauciarticular and systemic). Specifically, data will include: the number of joints affected by active arthritis, the result of lab tests and the functional status of the children being studied. By examining the course of each of these types of arthritis in children with different racial backgrounds, Dr. Nanda hopes to increase awareness of disease prevalence and severity in a variety of populations in order to ultimately improve diagnosis and treatment.

In her project, Dr. Toruner is examining the role of vitamin D in Childhood Systemic Lupus Erythematosus (cSLE), an inflammatory disease which affects multiple organs and often leads to arthritis in the small joints of the hands, wrists, elbows, shoulders, knees and ankles. Dr. Toruner is testing the hypothesis that vitamin D deficiency is more common in individuals with cSLE and that it is directly related to disease activity and severity. If this is found to be the case, Dr. Toruner hopes that it may be possible to control cSLE symptoms (such as arthritis) with vitamin D replacement therapy.

The Chapter is extremely proud to sponsor these fellows and continue supporting top-notch researchers in the field of pediatric rheumatology.

Children with Arthritis *(continued from page 1)*

influximab. Many parents may be worried that the long term impact of these medications hasn't been extensively studied. While Dr. Gottlieb acknowledges that this is a serious concern, she explains that "deciding to take a medication is an individual choice. When making this decision, one needs to weigh out the risks versus the benefits in order to make an informed decision."

In addition to medications, treatment should take into account other factors such as promoting a well-balanced diet and

incorporating exercise into a daily routine, as well as addressing any social or emotional issues that may result from living with JA. Since many children with arthritis may feel isolated and different than their peers, it is critical to recognize these factors and address them immediately.

Dr. Gottlieb says, "One of the most important things to remember about treating JA is that with early diagnosis and recent advances in treatment, most kids with arthritis do extremely well. Families of children with arthritis should also remember that they are not alone! There are many resources at the New York Chapter that can help you learn more about this serious, yet treatable disease."

For more information about juvenile arthritis, or to request a copy of our free brochure, *Arthritis in Children*, please contact the **New York Arthritis Exchange™** telephone helpline at (212) 984-8730, or, from the 914 or 845 area codes only, (800) 246-2884.

The Ruth Chapman Revocable Trust remembered the Chapter with a bequest of \$1,000.

A distribution of \$6,813 from the estate of Sebastiana Ambrogio will support arthritis research.



Advocacy Update

Summit News

On March 2-4th, members of the Chapter's *Arthritis Advocates in Action* and other arthritis advocates from around the country attended the **11th annual Advocacy and Kids' Summit** in Washington, DC. Each year, this summit brings together advocates of all ages from across the country to meet with their Members of Congress and educate them about the devastating impact that arthritis has on those who live with the disease, their families and our country's economy. Faced with a large number of new Congressional Members in the 111th Congress, advocates attending the Summit were also able to introduce the Arthritis Foundation and outline our advocacy priorities to a new administration.

Federal Highlights

- On February 17th, President Obama signed **the American Recovery and Reinvestment Act (H.R. 1)**, which includes \$650 million for a Prevention and Wellness Fund that will provide for evidence-based clinical and community-based prevention programs (mainly funded through the CDC) and \$10 billion for research at the National Institutes of Health (approximately \$140 million for the National Institute of Arthritis, Musculoskeletal and Skin Diseases). Thanks to your advocacy efforts and that of the Arthritis Foundation, research and public health provisions with the aim to target more resources to arthritis research and prevention have been included in the final bill. The Arthritis Foundation will be advocating to the new Obama administration that 1) arthritis research needs to benefit from this stimulus funding and 2) Arthritis Foundation programs are evidence and community-based prevention programs that need to be supported throughout the nation.

- The critical and comprehensive **Arthritis Prevention Control & Cure Act** was reintroduced into the 111th Congress in February. This initiative hopes to 1) strengthen arthritis public health initiatives, 2) expand the reach of evidence based self-management activities such as weight control and physical activity, 3) ensure that limited federal funding for arthritis is used in the most strategic manner possible and 4) authorize a remedy to address the country's severe shortage of pediatric rheumatologists.

To learn more about the Chapter's advocacy efforts, please contact mgreco@arthritis.org or call (212) 984-8730.

NEW YORK CHAPTER



Take Control. We Can Help.™

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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

Dr. Christine Hom is a practicing pediatric rheumatologist at New York Medical College.

Q: What are some of the key challenges that children with arthritis face within a school setting?

A: Like all other school-aged children, kids with arthritis want to fit in with their classmates. This can seem difficult, since these children are often facing different obstacles than their peers, but it is entirely possible. Some of the challenges include:

- experiencing morning stiffness, which may make it more difficult for children to get dressed and ready for school
- having a hard time getting on a school bus or walking to school because of flare ups in joints
- finding it difficult to sit for long periods of time during class
- having trouble taking notes due to arthritis in their hands
- struggling with getting to class on time because of difficulties with walking
- experiencing difficulty participating in certain activities in gym class

Q: What solutions do you suggest to address these challenges?

A: The goal of any juvenile arthritis treatment is to bring these kids to a place where they are no longer facing joint-related challenges in or out of school. Luckily, there are a number of medications which have been proven to be extremely successful in reducing joint pain and swelling. There are also some simple, non-medical ways to begin addressing these obstacles. These strategies will likely involve some planning as



well as discussions between the parents, child and teacher. Some examples include:

- scheduling enough time in a child's morning routine to include a warm shower or bath, to loosen up stiff joints
- making sure that the child is able to get up during class and stretch his/her joints
- allowing the student to leave class a few minutes early in order to ensure that s/he will get to the next class on time
- ordering a second set of books to be kept at school, so the child does not have to carry books back and forth

Q: You mentioned the importance of discussions between parents, children and their teachers. Can you explain a little more about creating this "student support team"?

A: Every child with arthritis can benefit by having a team of parents, health care and school-related professionals who are working together to help create the best

possible environment in which the child can thrive. Parents can help facilitate this team by providing information about juvenile arthritis as well as indicating their child's specific medical needs. Conversations should include discussions about what the child is able to do, rather than focusing exclusively on limitations. Additionally, it may be beneficial to encourage communication between the child's physician and the school health services.

Q: What advice do you have for the parents of a child who has recently been diagnosed with some form of arthritis?

A: It is so important, especially for younger children, that the parents act as advocates. Of course, every child and family is unique and will have different individual needs, but, across the board, the key to successful advocacy is in education. Parents must be sure to educate themselves about juvenile arthritis, so that they can then be well equipped to educate their children, teachers, school nurses and, in many cases, other students about the challenges faced by children with arthritis.

Q: Lastly, what advice do you have for children who have recently been diagnosed with some form of arthritis?

A: I always tell my patients to remember to enjoy themselves and have fun! They should be encouraged to try activities that interest them and to participate to the extent they can. While there may be some limitations and modifications, children with arthritis should feel as though they can participate in many of the

same social, athletic and academic activities as their peers. I also encourage my patients to get involved with the variety of events offered by the New York Chapter such as the *Kids Get Arthritis Too!* Family Days. These events are not only fun and educational, but also allow kids with arthritis to meet other children who may be having similar experiences. They help to show children with arthritis how much they can do.

For more information about the challenges faced by children with arthritis, the events offered by the Chapter, or to order your copy of *When Your Student Has Arthritis: A Guide For Teachers*, please call the **New York Arthritis Exchange™** telephone hotline at (212) 984-8730, or from the 914 or 845 area codes only, (800) 246-2884.

The estate of Ella A. O'Brien made a bequest of \$5,000 to the Chapter.

Kids get Arthritis, Too Family Day



The Chapter is currently planning a series of **Kids Get Arthritis Too! Family Day** events to be held in Westchester, Manhattan and Brooklyn in the upcoming months. The first program of the year, **Family Day at the Castle**, took place on March 14th at The Castle Fun Center in Chester, New York and was a huge success! Stay tuned for more details on these exciting and FREE programs for children with arthritis and their families.

For those of you who have attended the **National Juvenile Arthritis Conference** in the

past, you know that it is a great event that brings together children with arthritis and their families from all over the country for a weekend filled with fun, inspirational and educational activities. **The 2009 Conference is scheduled for July 9-12th at the Hilton Americas in Houston, Texas.** The Chapter is also pleased to announce that we are currently planning for the 2010 Conference which will be held in Philadelphia. The New York Chapter, along with the Long Island, Upstate New York, New Jersey and Eastern Pennsylvania Chapters, has already begun collaborating on this program. For more information, please visit www.arthritis.org.



The October Fund

In 1996, the New York Chapter introduced a new source of support for children with arthritis—the October Fund. This important program enables children with arthritis to be *children* and to participate in their childhood as actively as possible. It also promotes public awareness of juvenile arthritis.

For Whom? The October Fund was conceived as a means of offering recreational opportunities to girls and boys with arthritis and other diseases characterized by chronic inflammation of the joints. The Fund specifically aims to reach children from families with limited incomes.

Doing What? The October Fund helps to cover the cost of summer day camps, sports, exercise, art and cultural programs, and other recreational activities.

For more information or to receive an application, please contact (212) 984-8730 or mgreco@arthritis.org

Let's Move Together!

Introducing the 2009 Arthritis Walk Community Heroes



This year's Battery Park Arthritis Walk Community Hero is Ethan Hamilton.

Ethan Hamilton is a sophomore at the Horace Mann School in Riverdale, New York. He was diagnosed with Systemic Onset JIA when he was six years old. Despite the active status of his disease, Ethan maintains a challenging course load at school. In addition to English and History, Ethan is particularly interested in studying Japanese language and culture. He has traveled to Japan over the last two summers because of this interest and also, to participate in a JIA camp that was held last August in Yokohama, where he was the only non-Japanese participant. In New York, Ethan has participated in a number of

Arthritis Foundation events and was recently involved in the 2008 *Kids Get Arthritis Too!* Family Day.

Ethan is honored to be this year's Battery Park Walk Community Hero and can't wait to celebrate the day with his friends and family. When asked about his experience with arthritis, he says, "I've faced many problems and hardships with arthritis, however it has shaped me into a tougher and stronger human being. If I could have the chance to change anything, I wouldn't."

As told by his parents, John and Kim Pelfrey:

Spend a day with **Lucas Pelfrey** and we guarantee it will be one like no other. He is the most athletic three year old we know, loves to watch *The Little Einsteins* and *The Mickey Mouse Club House* and always plays with his trucks and cars.

He was just two years old when he was diagnosed with Systemic JRA last September. He had been so sick for so long, we can recall almost breathing a sigh of relief when he received a diagnosis. Once Lucas started his treatment, he began to get better almost immediately.

As parents, the worst part is the unknown. We hear about all of the possible effects of systemic JRA, and yet we watch as Lucas runs around like a crazy three year old. We also see the more difficult side of this disease when his fevers spike or he yells for us to come get him out of bed on rough days. His brother and sisters know he has times when he is sick, and they love him for who he is. We all take his JRA one day at a time.

Lucas is very excited to be this year's Orange County Walk Community Hero. We look through the pictures from last year and he can't wait to do the walk again. Last year, we had t-shirts made that had his picture on them, which he loved! We still wear them and every time he sees them, he feels like a "star."

Don't miss the fun and excitement! Join the New York Chapter for one of the upcoming Arthritis Walks:

Battery Park Arthritis Walk Sunday, April 26th

Historic Battery Park
Registration: 8:30 am
Walk: 10:00 am

Orange County Arthritis Walk Saturday, May 9th

Thomas Bull Memorial Park
Registration: 8:30 am
Walk: 10:00 am

Westchester County Arthritis Walk Saturday, May 16th

Tibbetts Brook Park
Midland Avenue
Yonkers, NY
Registration: 8:30 am
Walk: 10:00 am

For more information about the Arthritis Walk, please contact Lissa Stuart at (212) 984-8725 or lstuart@arthritis.org or visit our website at www.arthritis.org.



Lucas Pelfrey is excited to be this year's 2009 Orange County Walk Community Hero

Dates to Remember

Metro Sportsmed Physical Therapy

For additional information or to register, please call: 718-369-8041 or visit www.metro-sportsmed.com

Spring Into Fitness

April 2nd

12:00-1:00 PM

4911 13th Avenue (between 49th & 50th Streets)
Brooklyn, NY

April 15th

12:00-1:00 PM

1309 Avenue J (corner East 13th Street)
Brooklyn, NY

Back Pain and Arthritis

May 7

7:00-8:00 PM

263 7th Avenue (suite 2A) (between 5th and 6th Streets)
Brooklyn, NY

Foot and Ankle Pain

June 4th

12:00-1:00 PM

380 Second Avenue - Ground Floor (corner East 22nd Street)
New York, NY

Hospital for Special Surgery

535 East 70th Street
New York, NY 10021

The Early RA Support and Education Program

The Importance of Diet and Nutrition

April 13th

4:30-6:30 PM

Sue Xiao Yu, RD, CDN

How Treatment Decisions are Made in Early RA

May 11th

4:30-6:30 PM

Stephen A. Paget, MD, FACP, FACR

Taking Care to Protect Your Joints

June 15th

4:30-6:30 PM

Yene Yoo, OTR/L, CHT

To register, please call Dayna Kurtz at 212-774-7378

Knee Replacement: Considerations Before Surgery

April 1st • 10:00 AM-12:00 PM

Friedrich Boettner, MD; Jason Metoxen, PT; Andrew Pearle, MD

To register, please call Jane Huang at 212-774-2793

Antiphospholipid and Antibody Syndrome (APS)

April 30th • 6:00-8:00 PM

Michael Lockshin, MD

To register, please contact Robyn Wiesel, at 212-774-7326

Rheumatoid Arthritis and the Importance of Staying Active

May 5th • 5:30-6:30 PM

Karen Yanelli, PT, DPT

To register, please call Jane Huang at 212-774-2793

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.

Visit these Features on our Web site

- Arthritis Advocates in Action
- Advocacy News
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Please visit us at our website at:
<http://newyork.arthritis.org>

A distribution of \$65,163 from the estate of Ethel K. Denney will support programs for people with arthritis.

Susan Ellman remembered the Chapter with a bequest of \$246.

**In the Next Issue:
Sports and Arthritis**