

Kids ^{get} arthritis ^{too}



A WELLNESS LETTER FOR FAMILIES OF CHILDREN WITH ARTHRITIS

JULY/AUGUST 2004

Who's Caring for Our Kids?

By Mary Anne Dunkin

Half the kids in this country live more than 50 miles from a pediatric rheumatologist. Who will treat them if they have arthritis?

When Robert Hernandez was only 4 years old and began experiencing knee pain, his pediatrician dismissed his symptoms and told his parents they would probably go away with time. His mother, however, was not convinced. She packed him in the car and drove two hours from their home in Muncie, Ind., to Indianapolis to see the only pediatric rheumatologist in the state. For that doctor, Murray Passo, MD, the reason for Robert's symptoms didn't take long to figure out – he had an aggressive case of juvenile rheumatoid arthritis.

Robert became a regular patient of Dr. Passo, frequently making the four-hour round trip to his office. Five years later, when the Hernandez family moved to Dayton, Ohio, the round trip grew to six hours, but they scarcely considered taking their son elsewhere. Dr. Passo's expertise and the trust they established were rare. So were doctors

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Have You Had 'The Talk'?

By Sara Baxter

Talking to teens with arthritis about sex, drugs and alcohol may be uncomfortable, but the dialogue could be a life saver.

Whenever Marcia Imbrescia's teenagers are faced with making a decision, she wants them to hear her voice in their heads.

The Lynnfield, Mass., mother of two has talked to them over and over about

sex, drugs, alcohol and other issues teenagers face. She's used role-playing, books, school resources and frank discussions to educate her children to prepare them for any situation.

"Part of being a good parent is talking about these things," says Imbrescia, whose 16-year-old daughter, Stefanie, has juvenile rheumatoid arthritis (JRA). "Kids can make wise decisions. You just need to give them the tools."

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Kids Get Arthritis Too

A Wellness Letter

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For more information on juvenile arthritis and related conditions, contact the American Juvenile Arthritis Organization, a council of the Arthritis Foundation, at 404/965-7538, or visit our Web site at www.arthritis.org.

Kids Get Arthritis Too (ISSN#1524-5144) is published six times each year by the Arthritis Foundation Inc., 1330 West Peachtree St., Ste. 100, Atlanta, GA 30309. As of Jan. 1, 2001, new subscriptions are available free with Arthritis Foundation membership, thanks to a restricted grant from Amgen Inc. and Wyeth-Ayerst Laboratories. POSTMASTER: Send address changes to *KGAT*, P.O. Box 921907, Norcross, GA 30010-1907. ©2004 Arthritis Foundation Inc. Material in this publication may not be reprinted without written permission from the editorial offices in Atlanta. Printed in the U.S.A.



Q & A With Kevin Brennan

By Bethany Afshar



Met Kevin Brennan. As senior vice president, Public Policy and Advocacy, for the Arthritis Foundation, he's working to ensure your voices are heard on Capitol Hill. *Kids Get Arthritis Too* sat down with Kevin recently to learn more about advocacy and what's going on in Washington, D.C.

What were the three key legislative items at this year's Advocacy Summit and Children's Summit?

Two hundred advocates, including almost 40 children, visited with Congress to ask for more funding for arthritis research and public health funds, increased access to medications for people with arthritis who depend on Medicare for their health care coverage, and action on national arthritis legislation.

In addition, more than 12,000 advocates from across the country also urged Congress to act on our priorities via the Internet during our Virtual

Advocacy Summit.

What has happened with those legislative items since then?

These folks have really made a difference. On May 22, the Senate introduced S. 2338, the Arthritis Prevention, Control and Cure Act. The bill is the first significant federal legislation to address arthritis in almost 30 years. The bill would accelerate federal efforts to support arthritis research and public health initiatives as well as address

several important issues facing children with arthritis.

The bill would authorize the Centers for Disease Control and Prevention (CDC) to study – for the first time – how many kids are affected by arthritis. It would authorize the National Institutes of Health to increase funding for juvenile arthritis research. It would also establish a federal program to expand the number of pediatric rheumatologists who treat kids with arthritis.

What can *KGAT* readers do to help get Congress to pass the bill?

It is critically important that families let their senators and representatives know that Congress can do something important to help kids by co-sponsoring the bill. Co-sponsoring a bill is just a fancy way of saying they publicly support the bill. The more members who co-sponsor it, the greater chance of Congress passing it this year. It's fast, it's easy, and it can change lives.

Why is arthritis advocacy important?

Here's an example: the federal government is only spending \$7 million on juvenile arthritis out of a total federal biomedical research budget of \$28 billion. This translates into approximately \$20 per child with arthritis. This isn't right. But we can only change it if every single family with arthritis gets involved in the fight to pass the arthritis bill. If we don't urge Congress to help kids with arthritis, how can we expect things to change? ★

See Page 4...
for breaking news
from Capitol Hill.

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Publication of *Kids Get Arthritis Too* is made possible thanks to an educational grant from Amgen Inc. and Wyeth Pharmaceuticals.

For free information about juvenile arthritis and its treatment, mail, e-mail or fax your response.

Yes, please sign me up to receive *Kids Get Arthritis Too*.

Yes, please send information about arthritis in children and the American Juvenile Arthritis Organization.

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Successfully Surfing the Web for Arthritis Information

By Linda Brown

The Internet can perfectly complement more traditional sources of information

Score one for the Internet! It offers those with arthritis a staggering amount of information and a way to connect with others going through similar experiences, all at the click of the mouse. But wading through the tons of data – not to mention the misinformation – can be daunting. Here are some guidelines to help you and your child navigate through the maze of arthritis information on the Web.

- **Talk to your doctor first.** Many physicians today are fairly Web-savvy and may be able to save you time by recommending reliable health Web sites. But will your doctors roll their eyes if you come to your next appointment with Internet data in hand? Some may, but Harry Gewanter, MD, a pediatric rheumatologist in Richmond, Va., is all for patients coming in with “stacks of printouts from the Internet” because, he says, “We can start our discussion at a different point, and I can provide context for that information so we can talk directly about what they’ve read.” (And, of course, check with your physician before acting on anything you find online.)

- **Narrow the search.** If you use a general search engine like Yahoo or Google, first click on “Directory” then go into “Health” and locate the arthritis section. Better yet, search with trusted sites such as the National Library of Medicine’s Medlineplus or the U.S. Department of Health and Human Services’ Healthfinder (see box).

- **Give the site a quick once over.** Before you dig into a Web site, check for some key components: who is the site’s sponsor and how often is the site updated? Look for an “About us” tab. Sponsorship will help you to figure out the Web site’s purpose. Medical

information needs frequent updating to remain current. Look near the bottom of the page for the date of the latest revision.

- **Watch for red flags.** An obvious danger sign is the promise of miracle cures for arthritis. Also look out for sites that require you to pay for information. There are plenty of sites that offer free information. You shouldn’t have to pay a registration fee to read about arthritis on the Internet.

- **Don’t go it alone.** Use the Internet to meet others with arthritis, exchange information and give mutual support. Ericka Umbarger, a recent graduate of Virginia Commonwealth University, has had juvenile rheumatoid arthritis for almost 11 years. She uses the discussion boards at the Arthritis Foundation Web site to discuss medications.

“With parental supervision for kids under 18, I think it’s a great way to meet other kids who have arthritis. It can be very lonely if you



think you’re the only kid out there who has arthritis,” says Umbarger.

Cooper City, Florida resident Marla Oxenhandler and her 14-year old son, Ricky, who has spondyloarthropathy, agree. Ricky uses e-mail to keep in touch with friends he’s met at camps for kids with arthritis. “As a parent, going to the Arthritis Foundation Web site over the years has helped me to see what other people are going through,” says Marla.

- **Avoid common mistakes.** A study by University of Michigan researchers about how teens search the Internet for answers to health questions revealed common errors that you should avoid. Misspelled search terms, not reading carefully enough through a Web site, and using too general or too specific search terms. ★

A Site Worth Seeing

A Guide to JA Information at www.arthritis.org

The Arthritis Foundation’s Web site offers lots of information for families of children with arthritis. Located in the “Juvenile Arthritis” section of the Communities segment of the site, you can research juvenile diseases and treatments, read about exercise and nutrition, find a physician, sign up for AJAO conferences or camps, learn about school issues, participate in message boards and order Arthritis Foundation publications. Check it out today!

Other Sites Worth Seeing

- **American College of Rheumatology:** www.rheumatology.org
- **National Institutes of Health:** www.nih.gov
- **National Library of Medicine:** www.medlineplus.gov
- **U.S. Department of Health and Human Services:** www.healthfinder.gov/kids
- **National Institutes of Arthritis and Musculoskeletal and Skin Diseases:** www.niams.nih.gov
- **From the medical experts of The Nemours Foundation:** www.kidshealth.org

One Boy Takes Arthritis to Capitol Hill... All the Way from Hawaii

By Linda J. Brown

Given the opportunity, 10-year-old Ryan Ariola likes what a lot of boys his age enjoy – playing baseball, riding bikes, fishing and swimming. But this spring, Ryan did something that most kids his age never get the chance to do. He traveled all the way to Washington, D.C., from his home in Hawaii to meet with some of the nation’s movers and shakers on Capitol Hill as part of the Arthritis Foundation’s Advocacy Summit.

Ryan’s passion about arthritis comes from personal experience with the disease. When he was 6 years old and a brand new first grader, he bent over to pick up a dropped pencil and his neck and jaw seized, almost as if he’d been in a car accident. When the severe stiffness and pain didn’t ease, he was placed in the care of two pediatric rheumatologists.

Seven months and many tests later, the doctors diagnosed Ryan with juvenile rheumatoid arthritis (JRA) and juvenile dermatomyositis.

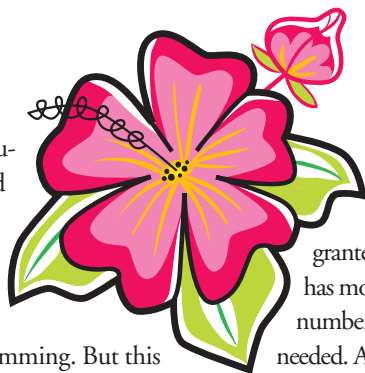
Adjusting to Life with Arthritis

Buoyed by his family, doctors and supportive teachers, Ryan hung in there.

“Ryan is a real fighter. He always tried, and he never gave up on anything,” says his mother Rachel.

After his diagnosis, Ryan’s doctors put him on naproxen (*Naprosyn*) then on prednisone and hydroxychloroquine (*Plaquenil*), and he responded very well to the medications. With the pain relief, he gradually got stronger, regained weight and made steady progress.

Ryan also benefited from weekend visits to a very warm pool where he worked with a physical therapist. “He learned how to swim at an early age and really likes it,” says Rachel. “Living on an island, you need to know how to swim.”



The Ariolas are thankful for the high quality of care Ryan received, something one may not take for granted when living on an island. But Hawaii has more pediatric rheumatologists than a number of states, though still not as many as needed. And Ryan is lucky he lives on the island of Oahu, just outside of Honolulu, with the Shriners Hospital only 20 minutes away.

Ryan’s condition improved steadily, and after two years on his medications, his doctors declared the diseases in remission and took him off the drugs. Steven, his dad, got him into a baseball league at the “late” age of 8. “And it’s clear that he’s become the most improved player on every team that he’s played on,” says Rachel. “He’s really catching up to the other kids, and his coaches just love him because Ryan has such a winning attitude.”

Advocates Through Thick and Thin

When Ryan and his family began dealing with his arthritis, they found out about the Arthritis Foundation and joined in several of the Arthritis Walks. At the 2003 walk, Ryan and Rachel were asked to speak. Shortly thereafter, Rachel became a board member for their local chapter. Mother and son began speaking at other Arthritis Foundation meetings and were then invited to attend the Advocacy Summit this past March.

The whole family, including Ryan’s 7-year-old brother Gavin, made the trip to the Capitol for the three-day event. “It was a phenomenal experience,” says Rachel.

They saw the sights, learned about the latest arthritis research and key arthritis legislation and met other kids with arthritis and their parents.

Ryan really enjoyed meeting the other kids and says, “It’s nice to know that I’m not the only kid with arthritis.” A hat signed by all the kids he met at the summit occupies a special place in his room so that he sees it when he wakes up every day.



The Ariolas with U.S. Representative Ed Case (center) from Hawaii

The trip’s high point, however, was the opportunity to talk with legislative leaders from Hawaii. “When Ryan spoke about what he went through and explained that there are a lot of other kids who have arthritis, his words had a large impact,” says Rachel.

Ryan really wants to increase awareness that it’s not just old people who can get this disease, Rachel says. “He liked getting a taste of politics” in Washington.

Indeed, Ryan admits that he may consider going into politics when he grows up. So in a few years, watch out for a Senator or Congressman Ariola from Hawaii. ★

Advocacy Update

A lot has happened since we interviewed the Ariolas and Kevin Brennan for this issue.

On June 8, the U.S. Senate Committee on Health, Education, Labor and Pensions (HELP) Subcommittee on Aging held a hearing on arthritis. Arthritis Foundation president and CEO Jack Klippel, MD, along with several Arthritis Foundation volunteers, including 19-year-old KaLea Kunkel from Oregon, Mo., had the opportunity to testify before the committee and garner support for the Arthritis Prevention, Control, and Cure Act of 2004 (S.2338).

Then, on June 17, U.S. Representatives Chip Pickering (R-MS) and Anna Eshoo (D-CA) introduced the House version of the bill (H.R. 4610).

Your support is needed now more than ever. Urge your representatives and senators to support this important arthritis legislation. Visit www.arthritis.org/advocacy today!

who specialized in treating children with arthritis.

When Care's Not Close By

It has been almost 25 years since Robert Hernandez, now 30, first saw Dr. Passo. Though the number of pediatric rheumatologists has since grown from a mere handful, these specialized doctors are still too few and far between for the number of kids who need them.

Juvenile arthritis is one of the most common childhood diseases, yet pediatric rheumatology has one of the smallest number of doctors of any pediatric subspecialty – a problem that can be attributed to many factors,

including the lack of role models, intensive training required and relatively low salaries compared to other medical specialties, says Carol Lindsley, MD, professor and chair of pediatrics and section chief of rheumatology at the University of Kansas Medical Center in Kansas City.

The problem, however, is not just with the number of pediatric rheumatologists, but also their locations. “About 90 percent of doctors who specialize in treating rheumatic diseases in children are clustered around large cities,” says Dr. Lindsley. In fact, a study funded by the Arthritis Foundation and published last December in the journal *Arthritis & Rheumatism* shows that only half of the population under 18 lives within 50 miles of a pediatric rheumatologist.

That means half of children who could benefit from a pediatric rheumatologist probably live more than an hour's drive from one. And in some states, such as Idaho and North Dakota, where there are no pediatric rheumatologists, a trip to the doctor could literally require packing a suitcase.

Who Else Can Help?

Clearly, for many children, visiting a pediatric rheumatologist isn't feasible – at least, not on a regular basis. So what do their families do? Many families, as the Hernandez family first did, see their pediatrician or family physician for care. But many people – including the physicians themselves – are

concerned that these doctors aren't fully up to the task of treating juvenile arthritis.

In a separate Arthritis Foundation-funded study of pediatricians and family physicians, which was published in December in the *Journal of Rheumatology*, only 10 percent of the pediatricians and four percent of the family physicians felt that they were up to date on the latest advances in juvenile arthritis treatment.

Other families turn to adult rheumatologists for their kids' care. While only half of children live within an hour's drive of a pediatric rheumatologist, the aforementioned study shows that 90 percent live within 50 miles of either a pediatric or adult rheumatologist.

“About 90 percent of doctors who specialize in treating rheumatic diseases in children are clustered around large cities”

Yet some physicians are concerned that most adult rheumatologists also may lack the knowledge to treat kids. Children with arthritis tend to have treatment-related issues that adults don't, such as experiencing stunted growth from the disease or corticosteroid treatment, says Christy Sandborg, MD, chief of the division of pediatric rheumatology at Stanford University and an author of the study in *Arthritis & Rheumatism*.

More Doctors, More Training

In recent years, the American College of Rheumatology, the professional organization of doctors who treat arthritis, has undertaken several efforts to increase the number of doctors who practice pediatric rheumatology.

Although it is important to try to maintain and, if possible, increase the number of individuals who get trained in pediatric rheumatology, it is equally important to try to develop approaches to optimize the care that is provided by all those caring for these children, says Betsy Mellins, MD, associate professor of pediatrics in the divisions of pediatric immunology and transplantation biology and pediatric rheumatology at Stanford University School of Medicine.

“At the most fundamental level, this means doing the studies needed to identify the best

diagnostic and therapeutic approaches to these problems and then getting that information out to all those who care for these children,” says Dr. Mellins, who was also an author of the *Arthritis & Rheumatism* study.

For most doctors who treat children with arthritis, increasing their knowledge doesn't necessarily require attending clinical meetings. “The good news is that in this age of electronic communication and telecommunication, there are better and better ways of sharing that communication,” says Dr. Mellins.

One example of using technology to convey information is a collaboration in the works between the Arthritis Foundation and National

Institute for Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to develop a unique CD-ROM resource for physicians. This pediatric rheumatic diseases CD-ROM will contain basic information about diagnosis, treatment, latest research, and patient resources.

What Parents Can Do

If your child has arthritis, understandably you want to get him or her the best care. In most cases, that means seeing a pediatric rheumatologist. But what if the closest one is hours away?

“One approach is to speak to the pediatric rheumatologist at the closest medical center and get a recommendation for who in your area has a special interest in children with rheumatic diseases,” says Dr. Mellins, “because these doctors usually have a good, communicative relationship with the nearest pediatric rheumatologist.”

In some cases, a pediatric rheumatologist will see a child only occasionally, but will coordinate care with another doctor closer to the child geographically.

At Stanford, for example, pediatric rheumatologists try to identify doctors in all of their referral areas. “We help them by phone or e-mail and provide outreach education,” says Dr. Sandborg. “In many cases, we see the children only once or twice yearly and work with the doctor for the remainder of their care.” ★

Uncomfortable? Yes; Necessary? Definitely

While many parents and teenagers feel uncomfortable talking to each other about the tough issues that confront adolescents, experts say it's imperative to discuss such issues openly and honestly so that children are prepared to deal with them. For parents of children with chronic diseases, conversations about sensitive topics may not take place at all.

"There's a misperception that these issues don't pertain to their child [with arthritis]," says Jessica Weiner, author of *The Very Hungry Girl: How I Filled Up On Life... And How You Can Too*, which chronicles her battle with an eating disorder. "They forget these kids are teenagers. But talk like this helps them feel normal – it's reality. And it empowers them with information."

"It's a combination of not knowing how to approach sensitive topics and not thinking they have to," adds Deserae Constantineau, 29, of Milwaukee, who was diagnosed with JRA when she was 7. "For example, people with disabilities are often seen as non-sexual beings – parents assume sexual relationships won't happen. But that's wrong."

For adolescents with arthritis, these topics are especially crucial. Many arthritis medications that benefit teens with arthritis can harm them when mixed with tobacco, alcohol, drugs and sex. In fact, if a young woman with arthritis becomes pregnant, she may need to stop some or all of her medications. Certain arthritis medications – namely methotrexate, *Arava* and thalidomide – can cause severe birth defects.

"It's like we've said to parents all along that it's important to talk to their kids about these subjects, but we *really* mean it this time," says Richard Vehe, MD, director of pediatric rheumatology at the University of Minnesota. "With kids with arthritis, it can be a matter of life and death."

Food, Drink and Drugs: Other Sensitive Issues

If you think you don't have to discuss drugs or alcohol with your kids with arthritis

because they already take unpalatable drugs – think again.

Research has shown that even kids who dislike the taste of their medication are just as likely to experiment as other kids. They may even be more inclined to succumb to peer pressure in an effort to "fit in" or to be daring. In a 1998 study, researchers found that out of 52 teens with arthritis surveyed, alcohol use was reported by nearly 31 percent, including 23.5 percent of those who were taking methotrexate. Tobacco use was reported by 15 percent of the teens, and 13 percent admitted using other illicit substances in their lifetime.

Aside from the obvious risks, it's important that children and adolescents understand that drugs and alcohol may cause an adverse effect when mixed with certain medications. For example, drinking alcohol while taking methotrexate could increase the medication's side effects. It can even damage the liver.

"Parents need to communicate the risk of the interaction between drugs and alcohol and certain medications," says

Constantineau. "Kids think 'it won't happen to me.' But it does."

Eating disorders are another topic that can be difficult to explore. At a time when body image is everything, teenagers are especially vulnerable to eating disorders – be it anorexia, bulimia, compulsive overeating or obsessive over-exercising.

Some teens have mitigating factors beyond their control, which could lead to

body image problems and even an eating disorder. For instance, certain arthritis medications, such as prednisone, can cause weight gain. Inactivity due to the illness can make it hard to ward off extra calories. And emotional eating may be a factor for a teen who feels isolated or like he or she doesn't fit in.

"Mix all this together, and it's a cocktail for an eating disorder," says Constantineau, who also struggled with body issues during her teen years. "Teenagers are bombarded with images of the perfect body. Parents need to start early with positive reinforcement and building a child's self-esteem." ★

"Kids can make wise decisions. You just need to give them the tools"

Watch for Teachable Moments

So how do you talk to your kids about the tough things? Be open. Be honest. And be brief.

"Kids pick up on things that are phony," says Michael Rapoff, PhD, a professor and chief of behavioral sciences at the University of Kansas Medical Center in the department of pediatrics. "Don't get preachy, and don't talk too much. When their eyes glass over and roll back, you know you've gone too far."

The first step in opening a dialog with your child is to become informed. This may involve reading books, consulting with health care professionals, talking with other parents – all to prepare you to spot warning signs of drug use, alcohol abuse, eating disorders and sexual activity.

Experts advise parents to take advantage of "teachable moments." If you see something in the newspaper or on television, or if your child talks about one of his or her friends, then use that as a chance to discuss the issue. If necessary, schedule a time to talk with your child about whatever is on your mind – or theirs.

"If you make communicating part of a routine, kids come to expect it," says Mark Detzer, PhD, assistant professor of psychiatry and pediatrics at Dartmouth Medical School and a clinical psychologist. "Make sure you promote a dialogue that is conducive to open and honest communication."

RESEARCH Updates

By Mary Anne Dunkin

Stopping Methotrexate After Remission

For many children with juvenile arthritis, treatment with methotrexate induces a remission of the disease. Yet doctors are sometimes concerned that a patient's arthritis will return if methotrexate is stopped too soon after remission is achieved.

To determine whether the timing of stopping methotrexate influences the length of remission, German doctors followed up two groups of pediatric patients who had achieved remission through methotrexate therapy. One group had continued to receive methotrexate for an average of 3.8 months after remission was documented; the other group received the drug for an average of 12.6 months afterwards. On follow-ups, doctors analyzed the children's blood levels of two proteins associated with inflammation of the joint lining: myeloid related proteins 8 and 14 (MRP8/MRP14).

When looking at the number of relapses between the two groups, the doctors found no difference in relapse time between those who stopped soon after remission and those whose treatment was prolonged. However, children with higher levels of MRPs experienced more relapses than those who had normal blood levels of the protein.

The doctors concluded that MRP8/MRP14 levels may indicate residual disease activity not evident through disease symptoms or other blood tests and should be taken into consideration when determining how long to continue methotrexate following apparent disease remission.

Source: *Annals of the Rheumatic Diseases*, Vol. 63, No. 2

Cyclophosphamide Helps Severe JDM

For children with severe juvenile dermatomyositis (JDM) that hasn't responded to more conservative therapies, treatment with intravenous (I.V.) cyclophosphamide (*Cytosan*) may offer much-needed relief with a low risk of serious side effects.

To determine the safety and effectiveness of the strong immunosuppressive drug for JDM,

a group of London doctors reviewed the records of 12 children who had undergone I.V. cyclophosphamide treatment. After six months of therapy, 10 of the 12 children had significant improvement in a number of areas including muscle strength, skin disease severity and overall disease severity.

The children also experienced reductions in several laboratory measures of inflammation and disease activity such as erythrocyte sedimentation rate and creatinine kinase and required lower doses of corticosteroids. Furthermore, improvement was maintained at the latest follow-up, which ranged from six months to seven years after treatment.

The side effects observed – including low-white-blood-cell count, hair loss and herpes infections – were not serious and resolved after treatment ended. Further studies and follow-up are needed to determine if any long-range side effects occur.

Source: *Rheumatology*, Vol. 43, No. 4

Blood Test Detects Lung Involvement in Kids with Scleroderma

Pulmonary fibrosis, or scarring of the lungs, is a serious potential complication of juvenile systemic sclerosis (JSS) that doctors must consider and look for in children with the disease. Yet, tests such as pulmonary function tests and CT scans used to diagnose and evaluate the problem can be difficult for young children.

A recent study suggests there may be an easier way to detect the problem: a blood test to measure a protein called KL-6. KL-6 is a protein made by lung cells, and blood levels of KL-6 have been found to be elevated in diseases characterized by pulmonary fibrosis.

To determine if KL-6 levels would be useful in detecting lung involvement in children with systemic sclerosis, a group of Italian and Slovakian doctors performed tests to check level of the protein in the blood of 12 children with the diffuse cutaneous form of JSS (six with lung involvement and six with-

out) as well as 20 healthy children. They found that levels of KL-6 were significantly higher in the children with lung disease than in healthy children and children with JSS but not lung disease. Furthermore, the levels correlated with lung capacity.

Based on their results, the researchers say KL-6 measurements can be effective in evaluating lung involvement and unlike other methods, it is easy to perform and measure repeatedly and it doesn't require the child's cooperation.

Source: *Journal of Rheumatology*, Vol. 31, No. 4

Quality of Life in Kids with Arthritis

When it comes to rating quality of life in children with arthritis, parents often give children lower ratings for their children than the children do themselves, a new study shows.

When Australian doctors asked 59 young patients and their parents to complete separately a number of questionnaires and measures on various issues such as pain, functional disability, and ability to cope, the parents reported significantly lower scores (indicating worse health-related quality of life) than did children on five of the eight scales.

The two groups did have some reporting similarities. Both reported a significant negative relationship between pain levels and quality of life on a test assessing children's physical, emotional and social functioning. Both also reported a significant negative relationship between scores on several pain-coping scales and scores on quality-of-life scales. However, the pattern of these relationships varied for reports from parents and children.

The study's authors say their findings confirm that pain intensity and pain-coping strategies have a significant impact on a child's quality of life. The differences in reporting, however, emphasize the importance of clinicians obtaining information about children's health-related quality of life, pain levels and pain coping strategies from both parents and children.

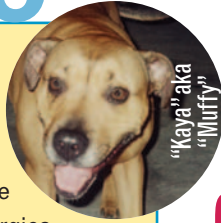
Source: *Rheumatology*, Vol. 43, No. 3

ask the experts

HELPFUL HINTS FOR CAREGIVERS AND KIDS

Can Having a Pet Make You Smarter?

In the last issue of *Kids Get Arthritis Too*, we told you about how pets can boost your immune system and reduce your chances of developing allergies.



Well, guess what? There's more good news. Gail Melson, a professor of child development and family studies at Purdue University, has studied the role of animals in children's lives and

has found that pets may help children develop their minds and language skills, too.

Melson is also author of the book, *Why the Wild Things Are: Animals in the Lives of Children*.

Kids: Don't Cut Carbs Just Yet. Just because a low-carb diet might have helped your mom drop a dress size or two, don't assume it's right for you, even if you have some weight to lose. Children on low-carbohydrate, high-protein diets essentially are starving themselves of critical nutrients, which may take a serious health toll on both the brain and the bones, experts say. Plus, a low-carb diet has no long-term effect on a child's weight, because it can't be maintained indefinitely. Instead of cutting your carbs, children should learn healthy eating habits that they can stick with for life.



Let Us Hear From You

If you're a kid or a caregiver with a question or some advice to share, send it to *Kids Get Arthritis Too*, 1330 West Peachtree Street, Suite 100, Atlanta, GA 30309 or e-mail us.

e-mail: kgatmail@arthritis.org

Representative questions and answers will appear in future issues. Letters may be edited. We regret that we cannot answer medical questions personally.

Q Our 13-year-old daughter has been begging for three years to get her ears pierced. I am concerned that her arthritis and the medications she takes (methotrexate and NSAIDs) may make her ears more susceptible to infection. My wife says it's no big deal and that letting her get pierced ears would help her morale. Do you think we should let her do it?

– J. L., Evanston, Ill.

A Sorry Dad, but I come down on the side of your wife and daughter. And it's not just because women stick together! Neither methotrexate nor NSAIDs will increase your daughter's risk of infection.

Understandably, many parents are concerned that methotrexate, which originally was developed as a cancer drug, will suppress the immune system

by killing off immune cells. At the high doses used for cancer, that can and does happen. But rheumatologists and pediatric rheumatologists use methotrexate in anti-inflammatory doses that are 300 to 1,000 times less than the doses used for cancer chemotherapy. These low doses are designed to reduce inflammation in the joints without killing off immune cells, so that the positive functions of the immune system still operate.

Your wife is also right about the positive effect on your daughter's morale. Thirteen-year-old girls want to be just like their friends, but your daughter's arthritis may make her feel a bit low at times because she feels different. Allowing her to have pierced ears may be just what the doctor ordered!

– Barbara S. Adams, MD
Pediatric Rheumatologist

Kids ask Kids

K.G. wants to know if he should go to the AJAO Conference. Here's what you had to say:

Yes, you should go. I don't have arthritis, but I have been two times with my little brother who has JRA. It is lots of fun, and you don't have to have JRA to go.

– S.C., Cincinnati

My sister [who doesn't have arthritis] likes going to the AJAO conferences as much I do. We swim, do crafts, play games. Who wouldn't want to go?

– J.E., via e-mail

Because kids come with their families, about half the kids at the conference don't have arthritis, so you won't feel "different."

– E.R., Atlanta

Can You Help?

Here's the next question for kids. If you have experience or advice to offer, please help out. We'll run selected responses in a future issue. Send answers or new questions to *Kids Get Arthritis Too* at the address to the left.

I was recently diagnosed with JRA and I have to have lot of shots. I also have to have blood tests. I hate needles. Is there any way to make this easier?

– K.B., via e-mail