

Kids ^{get} arthritis ^{too}



A WELLNESS LETTER FOR FAMILIES OF CHILDREN WITH ARTHRITIS

SEPTEMBER/OCTOBER 2004

Ready, Set... Transition!

By Sara Baxter

Making the leap from pediatric to adult care is an important – but sometimes overlooked – process

When Danielle Stephens went to schedule a regular appointment with her pediatric rheumatologist, she got quite a surprise. She found out that she could no longer be seen at the pediatric practice. Having just turned 19, she was too old.

“I had no idea this was coming,” says Danielle, who has polyarticular juvenile rheumatoid arthritis (JRA). “I had three months before my medications ran out, and I didn’t know what to do.”

Making the transition to what the American Academy of Pediatrics terms “developmentally appropriate” care is an important process for any late teenager or young adult –

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Achy Joints Take a Swim

By Linda J. Brown

Once you get kids in the water for aquatic exercise programs, you may have a hard time getting them out

Thursdays at 5 o’clock. That’s when her 10-year-old son Colin’s aquatic wellness group meets, and he doesn’t want anything to come between him and his class. He’s been attending the group at Cincinnati Children’s Medical Center Outpatient Drake Satellite for more than two and a half years, and he loves it.

Colin has progressive pseudorheumatoid dysplasia, a disease that resembles

rheumatoid arthritis. His knees, shoulders, ankles and hips bother him the most but Karen has noticed improved range of motion in his shoulders and arms since he got into the swim of things. He also takes less pain medication.

Colin succinctly says, “It just makes me feel better.”

While aquatic classes for adults with arthritis are easy to find, similar classes for kids are more of a rarity. But with summer over and many outside pools closed, you may want to seek out such a program because the benefits are many.

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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.



Caring for Kids with Arthritis – By the Book

By Mary Anne Dunkin

Kids Get Arthritis Too recently spoke with *New York-based pediatric rheumatologist and author, Thomas J.A. Lehman, MD, about his new book, It's Not Just Growing Pains: a Guide to Childhood Muscle, Bone, and Joint Pain, Rheumatic Diseases and the Latest Treatments (Oxford University Press), and his reasons for writing it. Here's what we learned:*

Can you briefly describe your book?

It's got three parts. The first part is basically to help parents figure out what is going on. If you already know what's going on, you can go to section two – a description of the rheumatic diseases and related conditions – so you can understand what the different diseases are. The third section deals with living with a child with a chronic condition: what the medicines are, what kinds of things your doctor can and can't do, understanding the tests your doctor is ordering and then what you need to do as a parent – your own individual responsibility to get the best outcome for your child.

Why did you decide to write this book?

I wanted to educate parents so they could help their children. When you take care of children like I do, pretty quickly you understand that the real problem is not that we need new drugs or new genetic tests. Most children who don't do well don't do well because they have had disease for a long time that was dismissed as growing pains or otherwise misdiagnosed, so too much damage has been allowed to occur before they get to the proper doctor. If those parents understood not to just dismiss their children's complaints for so

long, and if physicians were better educated about what is really going on and didn't dismiss these kids for so long, then these children would get to the proper doctor sooner, get treated better and have a far better outcome. I practice in the middle of New York City.

I see a lot of kids who have been to other doctors and have significant disease. Almost every child I see, the parents say "Gee, I didn't realize anything was wrong," or "We went to the doctor and he just thought it was growing pains."

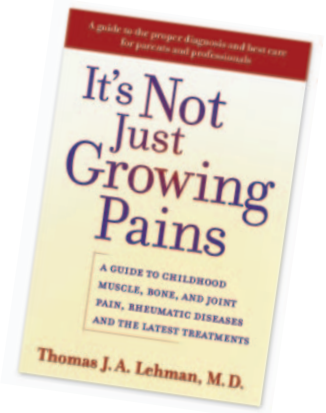
How long did it take for you to write it?

The book is 140,000 words, 400 pages. The answer is it took about a year of weekends to write the book, but it took 20 years to know what to say.

Do you have any final words of advice for readers?

I think the thing I would emphasize is that the key to getting the best outcome in children is to get them early and start the problem. Get in, find the problem and fix the problem. It's always easier to put out a fire than to fix charcoal.

It's Not Just Growing Pains is available at bookstores now. For more information, visit Dr. Lehman's Web site, www.goldscout.com. Dr. Lehman is senior scientist, attending physician and chief of the Division of Pediatric Rheumatology at the Special Surgery and professor of clinical pediatrics at Weill Medical College of Cornell University in New York. ★



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Teen's Testimony Before Senate Urges Passage of 'Arthritis Act'

By Mary Anne Dunkin

KaLea Kunkel isn't one to let anything stand in the way of her dreams – not even scleroderma, a life-threatening autoimmune disease that causes fibrosis or hardening of the skin and internal organs.

The 19-year-old college sophomore, whose disease began when she was barely out of diapers and has since affected her skin, esophagus, intestinal tract, thyroid and lungs, can't remember a time when she didn't have to deal with the daily battles of her disease. Nor can

rheumatologist's office from her home in rural Kansas. For the latter, she was grateful – at least she had a doctor who knew how to treat her disease, she told the committee. "I was fortunate that we had a pediatric rheumatologist nearby. Many children aren't so fortunate. Many don't have a pediatric rheumatologist in their state to provide them with the care I received."

Forty-nine years ago, one of those children was Virg Jones, who gave his testimony along



Sen. Bond, shown with KaLea, introduced the arthritis legislation in the Senate.

government only spends \$7 million on juvenile arthritis research each year, which translates to less than \$23 per child with arthritis. The total federal research budget is \$28 billion.

At Home in D.C.

Although testifying before the Senate was a first for KaLea, neither public speaking nor advocacy are new to her. "I have done health advocacy along side my mom [AJAO President Ann Kunkel] since I was 12," she says. "I started speaking for the Arthritis Foundation about four years ago."

Much of KaLea's advocacy work has taken her to Washington, D.C., where she developed an interest in politics and fell in love with the "energy and history of the city." Last year, her love prompted her to leave her home and move halfway across the country to attend George Washington University.

Despite her disease and its complications, KaLea has always been involved and active. Today, while at school she works part-time for the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

After college, KaLea plans to continue advocating for people with arthritis, perhaps lobbying on Capitol Hill for a while, she says. After that, she may pursue a career in public health administration.

Her advice to other kids and adults in her situation: "Don't give into [your disease] because it's not going away. Keep a positive attitude about what's going on and use it as a motivator. You've got to chase your dreams." ★

“The government only spends \$7 million on juvenile arthritis research each year, which translates to less than \$23 per child with arthritis”

she recall a time when she let her pain keep her from pursuing her dreams – including the dream that all kids with arthritis would have access to the best possible health care.

Miss Kunkel Goes to Washington

That's why KaLea played an important role in educating U.S. Senator, Kit Bond (R-MO), and his staff about the challenges facing kids with arthritis. This led the Senator to partner with the Arthritis Foundation on the development of historic legislation that will help both kids and adults with arthritis. On June 8, KaLea was invited to testify before the Senate Health, Education, Labor and Pensions' Aging Subcommittee.

She described her life with scleroderma – of wearing rubber gloves to carve pumpkins with her second-grade class, yet having a skin reaction anyway; of leaving class frequently to take medicines and receive breathing treatments; of seeing the skin on her hands, feet and legs crack and bleed; of going without food until she was dizzy because that was preferable to vomiting blood; and of making the four-hour round trips to her pediatric

with KaLea. Jones, who is now 62, was diagnosed with juvenile arthritis at age 13 when there were few doctors who treated the disease and even fewer effective medications for it. By the time he was in high school, Jones faced numerous joint surgeries and a lifetime of disability.

The legislation Jones and KaLea were there to support – the Arthritis Prevention, Control and Cure Act of 2004 – seeks to help improve access to specialty care for kids with rheumatic diseases by establishing a limited loan repayment program for medical students who decide to pursue a career in pediatric rheumatology. It also provides grants for those who conduct or promote the coordination of research, training and studies related to the prevention of arthritis and other rheumatic diseases. Currently, less than half of the children who need treatment are receiving it by a pediatric rheumatologist, she told the Senate. "This program could mean the difference between life and death for kids with juvenile arthritis and rheumatic diseases."

It will also authorize the National Institutes of Health to dramatically increase funding for juvenile arthritis research. Currently, the

Overcoming Arthritis...Artfully

By Bryan Powell

This effervescent teen joined others to tackle arthritis through art and to raise money for the Arthritis Foundation



Artists McCrea Clemons & Jennifer Jones

Jennifer Jones enjoys many of the activities of a typical 13-year-old girl. But, this eighth-grader from Kansas City, Mo., is not at all typical. First of all, she's positively effervescent in conversation. She speaks with precocious confidence, a trait no doubt owing in part to her parents, both of whom work in radio.

Jennifer also has juvenile rheumatoid arthritis, which at various times has affected her knees, ankles, toes, jaw, neck, wrists and fingers. Doctors diagnosed her illness when she was one-and-a-half years old. She enjoyed several years of remission beginning at age six. However, she's had active joint involvement for the last three years or so, limiting her strength and range of motion for sports and such everyday activities as turning on the shower or climbing stairs.

Still, Jennifer counts her blessings. "I understand how lucky I am, because it can be so much

worse," she says. "It makes you think twice about making fun of people with disabilities, or about not wanting to run a race because your knee hurts a little. It teaches you a whole other side about being respectful."

Like many children, Jennifer benefits dramatically from medications. She takes a weekly 10-milligram oral dose of methotrexate and twice-daily *Naproxen*. However, her *joie de vivre* seems more rooted in a resilient nature and a commitment by her parents, who are divorced, to give her every opportunity to succeed.

"We know she has limitations," says Jennifer's mom, Susan Wilson. "I notice myself trying to embrace anything she has a natural ability at and going all out to help her overachieve in those areas."

Arthritis Meet Art

Jennifer participates in Children's Miracle Network activities and Arthritis Foundation functions, including last year's Jingle Bell Run and Arthritis Walk, for which she was a spokesperson.

In April, Jennifer took part in Art for Arthritis, a local Arthritis Foundation fundraising event pairing young people with arthritis with local artists. Jennifer was one of 13 kids involved, collaborating with artist McCrea Clemons to create a painting, done in pastels, titled "The Keys to Success."

Jennifer and Clemons discovered that they both enjoyed music and played piano, so they spent a day at a Kansas City Jazz Museum getting acquainted and brainstorming ideas for the project.

When it came time to actually do the painting, "we both did our part, working together," Jennifer says. "She taught me how to draw certain parts, and she drew the really complicated parts and taught me how to shade them in."

The design (shown left) features a small figure at the top keyboard. "Jennifer suggested the figure," Clemons says, "to emphasize the fact that you can overcome. It's a spiritual thing, a 'reaching the top' metaphor."

As for spirit, Clemons was impressed with Jennifer's. "She had a lot more tenacity than most children, probably because she didn't want to appear different. She really has a zest for life; I never heard her complain."

Clemons learned something from the process as well. "I've grown to understand the challenges that Jennifer may face, and that kids just want to be accepted. All you have to do is accept them and listen; be their support."

The event culminated in a silent auction. The painting Jennifer and Clemons created sold for \$350. Collectively, the artwork from the event sold for \$12,125 and total proceeds from the event – including cards, calendars and the like – have exceeded \$27,000.

"I'd definitely recommend it for other kids," Jennifer says. "It's fun. You get to do artwork and raise money for a great cause at the same time. It feels good inside, too, when you do that. It's something I'd want to do every year."

Another primary function of the event was to get more children and families involved in Arthritis Foundation activities, explains Christy Simons, special events coordinator with the Western Missouri/Kansas City chapter. Only three of the 13 children who participated had previously been involved with the Foundation. The results have been beyond Simons' expectations. "Almost every one of the kids is now involved in another one of our events," she says.

"Connecting with the [Arthritis Foundation] has been a key for us and I [would recommend it to] other parents who are confused, or lost," says Wilson. "It will make their lives better in a lot of ways. It makes us more content, more relaxed, more sure that everything's going to be OK." ★



especially those with arthritis, who need to switch from a pediatric rheumatologist to an adult rheumatologist. Because it carries both emotional and medical implications, it requires the attention of young adults as well as their parents.

The medical implications begin with the basic truth that just as pediatricians know kids, physicians in adult medicine know adults. “People with arthritis are susceptible to all the same diseases and health issues as healthy adults,” says Laura Schanberg, MD, associate professor of pediatric rheumatology, Duke University Medical Center in Durham, N.C. “Adult doctors know more about these health issues than those who deal exclusively with children.”

These health issues range from changing prescription medications to focusing for the first time on high cholesterol, high blood pressure and other conditions that get more attention later in life. They also can involve discussing sexuality and reproductive issues that don't always fall under the purview of pediatricians.

Adult doctors also are used to dealing with the adult systems of insurance and job disability and management.

Looking Down the Road: Issues and Independence

While no “magic age” exists for moving away from pediatric care, experts say that when a child reaches age 14, parents should talk with their teenager about working toward a transition. This gives the teen plenty of time to start taking responsibility for his or her care, finding a doctor he or she feels comfortable with, and understanding the adult health care system. Exactly when this transition takes place depends on the age and maturity level of the young adult, as well as the medical situation and insurance issues. Various checklists are available to determine readiness and identify areas that need attention.

Successful transition requires the young adults to take charge of their own health care, the parents to let go and the health-care team to support the process. It doesn't happen overnight. In teaching children to be independent, parents can start taking “baby steps” such as making and going to appointments alone, taking

Ways parents can prepare themselves...

- Find out the policies regarding the age and service policy limits for your child's pediatric/adolescent practice.
- Find out your health care insurer's policy regarding the age limit of services under pediatric/adolescent care.
- Begin discussing transition early with both your child and the health care provider.
- Request that your pediatric health care provider recommend an adult provider who is sensitive and knowledgeable of young adult and chronic illness issues.
- Find out how your insurer handles referrals and consultations for transition to adult health care.

Source: National Center for Cultural Competency – Georgetown University Center for Child and Human Development, University Center for Excellence in Developmental Disabilities: <http://gucchd.georgetown.edu/ncccltransition.html>

medication without reminders and refilling prescriptions.

“You want to start handing off responsibility when there's a safety net,” says Patience White, MD, chief public health officer at the Arthritis Foundation and professor of medicine and pediatrics at George Washington University in Washington, D.C. “And then celebrate when your child reaches each goal.”

Patricia Rettig, a nurse practitioner in rheumatology at the Children's Hospital of Philadelphia, advises practicing independence with “teen only” visits – when a teen spends part of the appointment alone with the pediatric team. “During this portion of the visit, teenagers have a chance to address adolescent issues or other concerns in private,” Rettig says. “They also gain confidence in communication with providers, reporting symptoms, concerns, or requesting information on their own, which is an expectation when they receive care from an adult rheumatologist.”

The Steps Leading to Transition

Adolescents need to be involved with the transition process, including choosing an adult rheumatologist. Parents and the healthcare team can help and advise, but the decision belongs to the young adult. Dr. Schanberg suggests sitting down with the adolescent to determine what qualities he or she is looking for, such as age, sex and location.

“The new doctor should be someone

they feel comfortable with, trust and who seems comfortable with young adults and their concerns,” Dr. Schanberg suggests.

The young adult's medical condition also plays a role. “If you have a complicated illness involving many body systems, such as vasculitis or lupus, you will probably want to see a rheumatologist affiliated with a university tertiary care center,” adds Rettig. “This way if you need to see other specialists, the care can be coordinated under one roof.” She adds that insurance also may dictate whom you may be able to see.

Stephens got a list of potential doctors from her primary care physician as well as friends who had arthritis and then started doing her own research. She checked out Web sites and called offices to ask about medication, treatment approaches, emergency procedures, and other topics. Based on her phone conversations, Danielle visited one practice and ultimately chose that doctor.

Stephens, now 25, graduated from college last December and moved from Philadelphia to Harrisburg, Pa., to take a job as community outreach specialist for the Central Pennsylvania chapter of the Arthritis Foundation. Once again, she had to change doctors. But this time, she had the tools she needed to make a decision – and made sure the move had no surprises. ★

In the Next Issue of Kids Get Arthritis Too...

KGAT continues its examination of transitioning into adulthood with a look at college, careers and co-pays and how to navigate the scary transition into financial independence.

Easy on the Joints

"I've never had a child in 16 years who has not liked the pool," said Susan Keller, physical therapist at the Children's Hospital & Clinics of Minneapolis and St. Paul. "Water is just a perfect place for kids or anybody with arthritis."

One of the key benefits of the water's buoyancy is joint protection. Because body weight and gravity are not an issue in the water, there's less pressure against joints as there would be on land. Many of these programs are held in therapeutic pools with water temperatures around 90 degrees, which helps muscles to relax.

“Water is just a perfect place for kids or anybody with arthritis”

Moving with greater ease in water can lead to gains in range of motion. And after a fun warm-up that might include bicycling on a noodle or walking forward, backward, sideways and on toes and heels, many of the programs focus on range of motion.

"Basically we work every joint you have from your neck down to your feet," says Julie Hillis, aquatics coordinator at the Harris Methodist HEB Hospital in Bedford, Texas, and co-founder of the H20PE program for kids.

Working the joints has paid off for some of the kids in Cheryl Miller's program at Children's Healthcare of Atlanta at Scottish Rite. "We've had some children that had a very hard time walking because their hips had literally gotten stuck in positions that didn't make getting around very easy," she says.

After working and strengthening their joints in the water, they gained range of motion and regained the ability to walk with their legs underneath them, not spread out. "That's important to these kids' self images, especially when they're at school and they

want to walk like their peers," says Miller who is a physical therapist.

Pain reduction also can result from water exercise as it has for Colin Barge. Eleven-year-old twins, Jamela and Jasmine Davis, experience fewer flares since they've joined Miller's program. The girls have juvenile rheumatoid arthritis (JRA), and their mother Marvela says, "Before the pool therapy, they missed 70 days of school in third grade. Last year, in fourth grade, they only missed 13 days."

Increased strength is another potential benefit, as most of these classes dedicate some time to strengthening moves. The water alone can provide resistance, which can be enhanced by adding webbed gloves, fins and water weights.

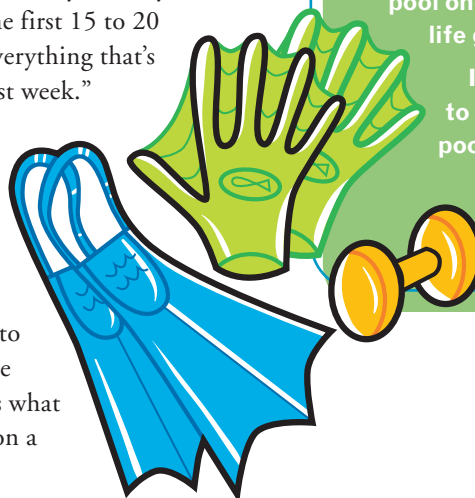
Aerobic activity in the water designed to boost the cardiovascular system is part of these classes, too. Running, jumping jacks, marching soldiers, robot walking, rocking horses, basketball, volleyball, swimming on a flotation device may be some activities used to get them moving and to get their hearts pumping.

The classes end with cooling down and stretching as you would do on land. Kelly Greve, MPT, who runs Colin's program as well as a teen group also lets her older kids do some Ai Chi (just like Tai Chi but done in the water) at the end to relax.

Group Support

Aside from the physical pluses, gathering kids together who are in similar situations facilitates wonderful benefits. Of Colin's group, Karen says, "They talk their heads off the first 15 to 20 minutes about everything that's happened the past week."

Miller sees advantages to group classes because "they learn so much from each other, and it's just nice to see somebody else who understands what you go through on a daily basis." ★



Where to Find an Aquatics Program Near You

Aquatics programs are not plentiful, so you may have to do a little legwork to locate one around you. Here are some tips:

- Check with your doctor, rheumatologist or physical therapist.
- Call your local Arthritis Foundation chapter (go to www.arthritis.org to find the nearest chapter).
- Check with your local YMCA. The Arthritis Foundation has a YMCA aquatic program for juvenile arthritis and an instructor training course.
- Contact the nearest children's hospital to see if they have such a program.

If you can't find an aquatics class from any of the above resources, make sure you express your interest in such a program to the people mentioned above. If you spark enough interest, you may be the catalyst to get a group started.

If there's no formal program in your area, another alternative might be a parent support/child recreational swim group. The North Central Minnesota chapter of the Arthritis Foundation has had such a program since 1987. While the parents meet, the kids splash around in a therapeutic pool on-site manned with a life guard and volunteers.

If all else fails, just try to get your child to a pool (not a cold one) so he or she can give his or her joints a break and have some fun.

RESEARCH Updates

By Mary Anne Dunkin

○ Mom's Cells May Cause Autoimmunity in Kids

For years, researchers have suspected that fetal cells, which can linger in women's bodies for years after giving birth, may somehow trigger autoimmune diseases in mothers. Now research suggests that the opposite – maternal cells that linger in children after birth – may trigger autoimmune disease in kids.

In a study of 72 children with juvenile dermatomyositis (a disease in which the child's immune system attacks and damages the skin and muscles), researchers found that 83 percent of the affected children had cells from their mother in their blood. (Mothers' cells can be identified by genetic markers on the cells.) In contrast, only 17 percent of healthy children had cells from their mothers in their blood.

The findings are important not only in seeking the cause and treatments of this disease, but also in understanding an entire class of autoimmune disorders, the researchers say.

Source: Journal of Immunology, Vol. 172, No. 8

○ Measuring Effect of Pain on Activities

For children with arthritis, recurrent pain frequently affects everyday functioning. However, few tools exist to measure the impact of recurrent pain on children's daily activities. Such tools, if they were available, could help health professionals identify targets for intervention and then measure how well children and adolescents respond to those interventions.

Researchers hope that a new measure, called the Child Activity Limitations Interview (CALI), will help health professionals do just that. In a study of 189 children with recurrent pain due to headaches, arthritis or sickle cell disease, researchers surveyed participants and their parents on demographic data, pain, anxiety and depression and functional disability (the inability to carry out daily activities).

About half of the participants completed daily diaries, in which they rated pain and activity limitations using the CALI survey and were surveyed again a month later.

Their findings showed that the CALI is a promising measure for assessing and monitoring subjective report of functional impairment in school-age children and adolescents with recurrent and chronic pain.

Source: Pain, Vol. 109, No. 3

○ Ultrasound Useful for Measuring Bone Density

For children with arthritis and related conditions, corticosteroid therapy as well as the disease itself can lead to dangerous bone loss. Because medical treatment can help slow or stop that loss, screening children with arthritis for bone loss is important. A new study shows quantitative ultrasound bone sonography (a procedure that measures the speed of sound waves through bone tissue) may be an effective screening tool.

In a study of 40 children with rheumatic diseases (32 with juvenile arthritis, six with lupus and 2 with dermatomyositis), 62 percent of whom were treated with corticosteroids, quantitative ultrasound of the radius and tibia yielded results comparable to DEXA of the lower spine, a conventional but more involved test used to assess bone loss. The researchers conclude quantitative ultrasound bone sonography might represent a promising means of evaluating bone quality in at-risk children.

Source: Journal of Rheumatology Vol. 31, No. 5

○ Diagnosing Bowel Disease in Kids

In children as well as adults, arthritis may be associated with inflammatory bowel disease (IBD), a general name often used to refer to two specific diseases – Crohn's disease and ulcerative colitis.

Although symptoms of the two diseases – including pain, diarrhea, intestinal bleeding, fever and weight loss – are similar, the optimal treatment for the two can be very different. For that reason, a specific diagnosis is often critical.

A new study shows that magnetic resonance imaging (MRI), coupled with the use

of the contrast dye gadolinium, can help doctors differentiate between the two diseases, which traditionally have required more invasive and unpleasant tests such as colonoscopy or colon tissue biopsy.

In a Johns Hopkins study of 58 suspected cases of IBD between 1999 and 2002, doctors discovered MRI with gadolinium (MRI-G) confirmed the diagnosis of ulcerative colitis in 92 percent of patients and the diagnosis of Crohn's disease in 96 percent of patients.

While MRI-G may never completely replace more invasive tests in the diagnosis of irritable bowel disease, the results show MRI-G is a useful sensitive diagnostic tool for the two conditions.

Source: Inflammatory Bowel Diseases, Vol. 10, No. 2

○ Kids with Chronic Diseases Become Well-Adjusted Adults

Pain, stiffness, tests, injections, medications and activity limitations - with all your child has to endure now, you may wonder how he or she will cope in adolescence and young adulthood when life stresses and hormone fluctuations wreak havoc with the healthiest of kids. A recent study, however, may help lay your fears to rest.

Researchers at Columbus Research Institute studied 125 young adults, between the ages of 18 and 20, with a history of cancer, sickle cell disease, or juvenile rheumatoid arthritis, as well as 125 of the participants' healthy friends. In interviews with the kids and their parents, the researchers found no differences in signs of depression, anxiety, post-traumatic stress disorder and other psychological problems between the two groups.

"Overall, we found that the effects of chronic illness do not necessarily lead to severe psychological impairment. These young adults were amazingly resilient," says Cynthia Gerhardt, PhD, pediatric psychologist at Columbus Children's Hospital.

Source: 2004 Pediatric Academic Societies' (PAS) annual meeting in San Francisco

Another Good Reason to Eat a Good Breakfast...

If getting up and out in the morning is difficult, you may be tempted to skip breakfast. Don't. In addition to providing the nourishment you need to start the school day, a new study suggests eating breakfast may provide another important benefit—preventing cavities! In the study, published in the *Journal of the American Dental Association*, young children who didn't eat breakfast each day had more tooth decay than those who did. A daily morning meal should be part of an overall healthful eating plan.

Meet Me in the Message Boards...

There's a new meeting place for young adults with arthritis, and it's right on the Arthritis Foundation's Web site, which has added a young adult section to its message boards. The Arthritis Foundation also hosts a message board for parents of children with arthritis. Check the boards out today at www.arthritis.org in the Communities section.

Congratulations Juliet Rizzo! The 36-year-old Rockville, Md., native has been crowned Ms. Wheelchair America 2005, representing the achievements of women with disabilities. Juliet will travel the country for the next year to speak and advocate on behalf of the more than 50 million Americans with disabilities. Juliet has been living with juvenile rheumatoid arthritis, fibromyalgia and scleroderma since she was 3 years old.

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.

ask the experts



Q My 15-year-old daughter has suspected lupus. Although she is doing pretty well medically, she is disturbed by a rash on her face. Is there any medication that will clear up the rash or cosmetics that will make it less noticeable?

— S.B., White Plains, Ind.

A Skin rashes are common with lupus and are often an early symptom of the disease. By some estimates, as many as three-fourths of people with lupus have skin rashes. Close to half experience a butterfly-shaped rash across the nose and cheeks. But that's not to say your daughter's skin rash is necessarily related to lupus. There are

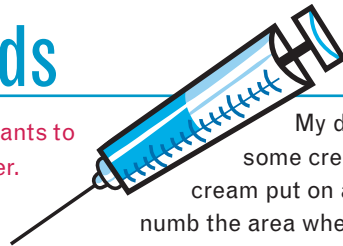
many causes for skin rashes, including acne, which affects most teenagers at some point.

I would recommend you work with your daughter's doctor to determine the cause of her skin rash and the best treatment for it. Because lupus rashes often develop or get worse in response to sunlight, it's important that she wear sunscreen every day (even when it's cloudy) and avoid direct sun exposure. Also, if her rash is caused by lupus, the medicine hydroxychloroquine is likely to be helpful in controlling it.

— Michelle Petri, MD
Rheumatologist

Kids ask Kids

K.B. hates to get shots and wants to know how to make them easier. Here's what you had to say:



I used to have a shot every day and I hated it! What helped me most was thinking how quickly the shot would be over. I would tell myself, "OK, for the next 30 seconds you will be getting a shot, but for the 23 hours, 59 minutes and 30 seconds after that you won't be getting a shot!"

— S.T., via e-mail

My doctor gave me some cream called *Emla* cream put on an hour before to numb the area where they are going to put the needle in. Then it doesn't hurt at all. After the test, my mom takes me to the toy store and I get to buy a toy. That helps, too.

— J.D., Onalaska, Wis.

If a person is REALLY good at taking blood, it shouldn't hurt hardly at all. When you find someone that's good at it, ask for that person each time

— J.B., Minneapolis

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 have arthritis in my knees that hurts and makes it hard to run in gym class. My teacher says if I get a note from my doctor, I won't have to take class, but I like gym class. What should I do?

— J.L., Boulder Colo.