Caring for Children with Juvenile Idiopathic Arthritis (JIA): A Parent's Guide

FIRST EDITION

Table of Contents

Table of Contents

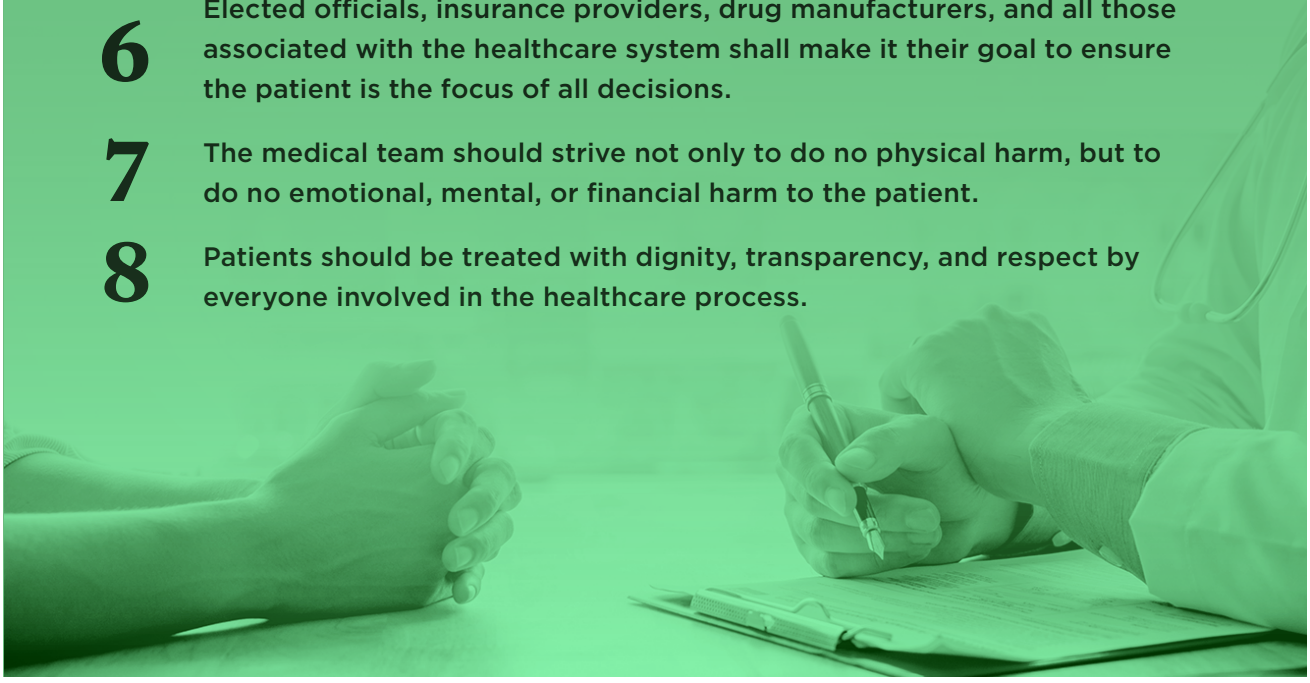
PART ONE

Patient Charter

CreakyJoints® is a patient-powered community of people with arthritis (and their families) that is part of the nonprofit Global Healthy Living Foundation. The CreakyJoints patient charter reflects our guiding principles, or the deeply held beliefs that drive our community's many efforts in arthritis education, support, advocacy, and research.

WE BELIEVE:

1. The patient experience is at the heart of medicine; thus the patient must be at the center of all medical decision making.
2. The medical process should stay between the patient and their care provider.
3. The patient should have access to all treatments deemed appropriate by their care provider.
4. Access to care should not be limited by external forces, financial or otherwise.
5. Patients should be empowered and educated with the tools needed to make their voices heard.
6. Elected officials, insurance providers, drug manufacturers, and all those associated with the healthcare system shall make it their goal to ensure the patient is the focus of all decisions.
7. The medical team should strive not only to do no physical harm, but to do no emotional, mental, or financial harm to the patient.
8. Patients should be treated with dignity, transparency, and respect by everyone involved in the healthcare process.



▲ The information in these guidelines should never replace the information and advice from your treating physician. It is meant to inform the discussion that you have with health care professionals, as well as others who play a role in your care and well-being.

Patient Charter

RAISE YOUR VOICE: Get Active, Advocate, and Take Charge of Your Health Care

Speak up at each doctor's appointment. **Bring a notebook** with you or **use your smartphone's Notes app** to write down information about your child's treatments, as well as your questions and concerns.

Write down questions or concerns ahead of time so you don't forget them at your appointments. Bring someone else with you, if you can, to help you take notes or ask questions.

Always ask about the costs of each potential treatment, as well as any possible side effects. Ask what might happen if you decide not to choose a certain intervention. Ask about your other choices or options.

Join other arthritis patients in local or national advocacy groups like CreakyJoints' 50-State Network.

Be an advocate to make sure your opinions and concerns are always heard by the people who create health care laws.

Use the power of technology! **Email or direct-message** other arthritis patients online on CreakyJoints' Facebook or Twitter pages, or on other social media platforms. As you get to know other patients, start one-on-one conversations on the phone or via text so you stay informed.

Add your name or sign online petitions with a simple click. You will make every advocacy effort stronger by joining with others.

Stay informed on social media and lend your voice to arthritis advocacy or health care issues when the time is right for you. Go online, sign up, join phone or email chats, share your thoughts, and attend live arthritis advocacy events when you can. Check out Facebook.com/CreakyJoints or @CreakyJoints on Twitter.

Tell your child's pediatric rheumatologist and nurses if your child seems anxious, depressed, or blue, or if they are not sleeping at night or able to get through the day because of any worries about arthritis. Remember, arthritis also affects the emotional health and well-being of parents, caregivers, and siblings. Seek care from a mental health professional or family counselor, depending on your child's and your whole family's needs. Find support and comfort from other families living with JIA that meet locally or online. Remember: You are not alone.

Share your opinion or experiences. Fill out patient surveys. Talk to juvenile arthritis advocacy groups looking for patient input on important health care issues. Offer your thoughts on Facebook or other social media (but remember that nothing is private online, so think about what you want others to know). You don't always have to give your name, but when it's appropriate, let others — including elected officials in your state government and at the national level — know that you are a constituent, you vote, and you care about these issues. Choose email, mail, postcards, social media, phone calls, or in-person meetings — whatever works best for you.

Stay informed and up to date. There may be ways for you to get help affording treatments, new treatments that may be more effective or affordable for your child, or clinical trials going on in your area. Follow CreakyJoints at www.creakyjoints.org for news and articles about patients like you to find out how others are dealing with treatments or coverage challenges. Follow @CreakyJoints on **Twitter,** or like the CreakyJoints Facebook page to hear news updates and share your thoughts. Also, check out the American College of Rheumatology's website, www.rheumatology.org, for news updates on

Patient Charter

rheumatic diseases like JIA and new treatment approvals. Other online resources that may be helpful for parents of children with a rheumatic disease include:

- kidshealth.org/en/parents/jra.html
- www.kidsgetarthritistoo.org
- www.carragroup.org
- www.printo.it
- www.niams.nih.gov

Speak up about your child's therapy side effects or concerns about any treatments. Don't feel that your child will just have to "put up with it" and don't downplay the side effects they are experiencing. Your doctor may be able to make changes to the treatment plan to help ease your child's side effects. Help your child speak up with any questions or concerns too, especially if they are very young.

Look for patient assistance programs from your child's prescription drug's manufacturer if you need help to afford copayments or coinsurance costs. Ask your doctor's office or pharmacy about any coupons or rebates available to you. Go online to find each drug's website, where these programs will be listed. Your family may be eligible for these programs, so find out. A great resource is: creakyjoints.org/support/arthritis-copay-cards-assistance

Call your insurance company to ask about the details of your family's drug coverage, **talk to your pharmacist** or **call your specialty pharmacy** to ask about your options or possible discounts. **Compare pharmacies' prices** if that's an option under your policy.

Ask your child's doctor about clinical trials. These are tests for new and existing therapies. If your child qualifies for a clinical trial, ask about any costs you may have to bear (such as travel to a clinic), or the trial's possible risks and benefits. You can learn more about ongoing clinical trials at the government's official website, www.clinicaltrials.gov. Each entry will have specific information about current clinical trials — or those which are now recruiting patients to participate — as well as contact information.

Talk to your pediatric rheumatologist about biosimilars. What are biosimilars? They are a new group of biologic drugs used to treat JIA and other rheumatic and many other diseases. Biosimilars are developed using existing, proven processes and formulas for biologic drugs that are highly similar. Several are FDA-approved for JIA. Biosimilars are not generic drugs, or exact copies of the biologic (often called the biosimilar's "reference" drug). However, they are developed to be as similar as possible. They may also cost less. Ask your insurance company or specialty pharmacy about your out-of-pocket cost for both the biologic your rheumatologist prescribed and its biosimilar, if there is one.

Ask your employer's (or your spouse's employer if that's how you're insured) HR department if your insurer has any patient advocate or employee assistance programs as part of your coverage. These advocates or advocacy programs are designed to work on your behalf to provide information or assistance related to your health care. If you feel that your payer is treating you unfairly when it comes to your coverage, **you have the right to fight back.** You and your doctor can appeal to get a drug or other treatment covered. You can also file a complaint with your state insurance commissioner's office. Check out their website (each state has its own insurance commissioner) or give them a call, even if you just have questions. ●

PART TWO

Introduction

Welcome to the first CreakyJoints guide for people caring for children with juvenile arthritis. Why did we create this guide for you, parents and caregivers of kids with JIA? It's designed to help you make decisions about your child's health in an ongoing partnership with your rheumatologist and other health care professionals.

Juvenile idiopathic arthritis is a disease that has many different forms. JIA affects as many as 294,000 children and adolescents in the U.S. today. Regardless of whether your child has lived with JIA for years, or has been recently diagnosed, this guide will give you more information about:

- Current treatment options;
- How these medications work;
- How your child will take these medications; and
- Possible side effects and tips for you to manage them

You'll learn practical tips for you and your child on ways to manage JIA symptoms other than by taking medications, such as at-home pain remedies, fun ways to get more exercise, diet and nutrition, tips for a good night's sleep and stress management. We will also share some information with you to help you and your family afford JIA prescription medications.

This first edition has been edited by leading doctors and health care experts, and will be updated and improved regularly as new research, information, and treatments on JIA become available. It's also been reviewed by parents of children with JIA, to make sure the advice is helpful and relatable.

WHAT ARE GUIDELINES?

This unique guide is based on current recommendations to treat and manage JIA, which were developed by a team of pediatric rheumatology experts — physicians who specialize in the diagnosis and management of children with arthritis and rheumatic diseases. "The American College of Rheumatology (ACR) Recommendations for the Treatment of Juvenile Idiopathic Arthritis," were published in 2011, and updated in 2013, in the medical journal ***Arthritis & Rheumatism*** (now called ***Arthritis & Rheumatology***). Other articles on JIA research have been published in its fellow publication, ***Arthritis Care & Research***. These guidelines were the result of a years-long, detailed process by an expert panel to review comprehensive data on available treatments to manage JIA.

What are treatment guidelines, and why do they matter to you and your child? Health care providers use these guidelines to make informed treatment decisions for JIA patients like your child. These guidelines help them select the best therapy for their patients, prescribe the most effective treatments, monitor and manage side effects, and watch for possible problems or signs that a drug may not be working as well as it could. They use these guidelines to help determine when it's the right time to switch to a new therapy to improve those results – and, ideally, to help your child reach remission. The American College of Rheumatology is the largest professional association of rheumatologists in the world, and is one of the leading organizations involved in the creation of treatment guidelines for patients with arthritis and rheumatic diseases, including JIA.

Something to keep in mind: Most children with JIA will have a treatment plan that includes a combination of different therapies: medications, exercise, physical and occupational therapy, a healthy diet, etc. Your child's treatment plan will be unique, not one-size-fits-all. Guidelines are just that: recommendations. They suggest common pathways that doctors can consider when they make treatment decisions, but your child's treatment plan should be tailored to his or her individual needs.

Treatment guidelines are updated on a regular basis to make sure that they contain the latest treatment options based on the most up-to-date research, as well as to reflect changes in medical technology, treatment standards and philosophies, as well as other aspects of care. However, since all children are different, your physician may select interventions that differ from current guidelines for various reasons. If that's the case, and you have any questions about why your child is prescribed a certain therapy, ask your doctor to explain this decision to you. Ask questions about the goals of these therapies, why your doctor thinks this is the right choice for your child's arthritis treatment, and whether there are other alternatives to consider.

Some current standard-of-care intervention options for JIA are not specifically FDA-approved for children with these diseases. Your pediatric rheumatologist may prescribe some medicines on an "off-label" basis. That means they are approved by the U.S. Food and Drug Administration (FDA) for use, but not specifically approved for this particular situation or disease. The FDA's current process for evaluating and approving medications includes three general "phases" to test the product for safety, clinical benefit, potential risks and efficacy. Some drugs may not be tested or approved specifically for a particular indication (which means a specific health condition), but it is still thoroughly tested for safety and efficacy in other, often very similar conditions.

It is important to remember that getting a drug approved for a specific indication may cost the drug company millions of dollars simply to include children after the drug is approved for adults. Since relatively few children have arthritis, drug companies often do not go through the additional costs of getting a drug approved for children that has already been approved for adults. The lack of FDA approval specifically for children doesn't mean the drug isn't safe for children and adolescents.

That's why your doctor may prescribe some drugs off-label. But keep in mind that payers (insurance companies) may deny coverage for off-label treatments, so speak with your doctor about any new prescriptions that may be off-label and not covered.

Want to learn more? Check out the FDA's quick overview of their drug approval process: www.fda.gov/Drugs/DevelopmentApprovalProcess/default.htm

This parent guide was created with you in mind. It contains easy-to-understand information that will help you better understand your child's treatments, both pharmacologic (meaning with drugs) and non-pharmacologic (not using drugs) in order to better help you and your child manage his or her JIA more effectively. It translates treatment guidelines for doctors into language that we all can understand.

HOW TO USE THIS GUIDE

JIA is something your whole family lives with on a daily basis. It is a family affair, like it or not, and everything involves all family members. There will be good days, not-so-good days, and difficult and horrible days. Your child may have flares that require immediate medical care, as well as days when long-term symptoms are hard to manage. There will be days when everyone forgets that your child even has JIA. Everyone will deal with setbacks, challenges, questions, and anxiety, not to mention insurance policy fine print, coverage changes, and tough decisions. Everyone will also deal with joy, success, resilience, surprises, and exceeding expectations.

Your pediatric rheumatologist and other members of your health care team — such as pediatric nurse practitioners, primary care provider, physical therapists, social workers, educational consultants, other specialists, and medical office staff — are your best sources of information about your child's care. In this guide, we'll try to help you make sense of medical jargon and acronyms: those often-confusing terms that you may hear or read about online. We'll share sample questions you might ask at your child's doctor appointments, and provide tips as to where you can find more information or help if and when you need it.

Every day, we are moving closer to a cure for JIA. We now have decades of medical research findings about JIA's causes, its similarities to and differences from adult forms of arthritis, and how best to manage this disease to give your child an active and fulfilling lifestyle. Research has led to the development of a number of new treatments and management approaches for JIA in recent years.

We expect the future to hold even more exciting treatment possibilities: genetic research to improve therapy response and prevent complications, precision medicine to deliver the right treatment to your child at the right time, and even new research that could tell us which children may be more likely to develop JIA before it happens. The ultimate goal is to find a cure, but until that happens, we need to treat every patient better.

More and better treatments are available now than ever before to control your child's joint pain and other symptoms, and to prevent severe joint or organ damage. In most cases we can modify the disease process before the inflammation can do serious harm. Children with JIA lead active, healthy, and fulfilling lives. They play sports, star in the school play, dance at their proms, and grow up to pursue careers and have their own families. Having JIA (or any chronic illness) does not stop people from living full and productive lives. Maybe you have to do some things differently, but you still can do them. ●

▲ The information in this parents' guide cannot and should never replace the information and advice from your child's treating physician. It is intended to improve your discussions regarding your child's care with your physicians, nurses, nurse practitioners, pharmacists, therapists, and other health care professionals.

PART THREE

What Is Juvenile Idiopathic Arthritis?

Juvenile idiopathic arthritis (JIA) is a group of chronic inflammatory diseases that occur in children under 16 years of age. These diseases primarily affect the joints, and their cause is currently unknown — that's what "idiopathic" means. While JIA primarily affects the joints, these are all systemic, chronic conditions that can also involve many other organ systems. Girls are diagnosed with JIA about twice as often as boys.

JIA is a group of diseases. This means that JIA is a collection of signs and symptoms with a recognizable and consistent course. There is no one specific test to diagnose JIA. Your child's diagnosis is made by applying criteria developed by an expert panel of pediatric rheumatologists. In the past, JIA often was called juvenile rheumatoid arthritis (JRA), juvenile chronic arthritis (JCA), or similar terms that may still be used at times.

Although JIA, by definition, begins in children before the age of 16, the disease may persist in some individuals. These children may have continuing disease and disability because of joint damage that persists in adulthood.

JIA is an autoimmune disease. Each person has an active **immune system**. This is a system of glands, organs, and various types of cells that all work in concert to fight off disease and keep your body healthy. The immune system may sense invading agents of disease, like bacteria or viruses, and send out these cells to attack and destroy them. But in an autoimmune disease, something goes haywire. Instead of your child's immune system fighting off outside invaders, it sees the body's own tissues as the enemy. In an autoimmune disease like JIA, your child's own immune system attacks joints, organs, and other tissues. This leads to inflammation, pain, fevers and, if untreated, serious damage.

In JIA, a child's immune system triggers inflammation in the synovium, the tissue that lines the joints. Normally, the synovial cells produce fluid that nourishes, lubricates, and cushions the joints, so cartilage and bones move easily. When the synovium becomes inflamed (also called synovitis), the joint is not lubricated. Destructive proteins are released into the joint space. As a result, the cartilage becomes damaged, and, in time, damage occurs in the associated structures. In response to the synovial inflammation, the affected joints swell, stiffen, and feel hot, tender, and painful. Your child will limit moving those joints.

If untreated, inflammation of the synovium (synovitis) may lead to long-term problems in the joint. Some effects may be minimal, but some children could have more limitations. The joint inflammation and/or injury may make even simple, ordinary tasks, like getting dressed in the morning, holding a pencil or turning a key in the front door lock difficult to perform. Since these are systemic conditions, the inflammation from JIA can also affect a child's other organs, such as the eyes. This is a condition called uveitis. Inflammation of the eyes from uveitis can cause swelling and tissue damage, so it's very important for your child to have regular eye exams with an ophthalmologist. Symptoms of uveitis include eye pain, redness, blurred vision, and sensitivity to light. Please note that there can be no symptoms until there is significant damage. Regular eye exams for your child are very important.

Here's the good news: Newer medications have been developed to target the sources of inflammation in kids with JIA. They can be very effective at treating and preventing joint problems. Children with JIA can grow and progress at a healthy rate, and enjoy all the physical activities they love: playing soccer or softball, swimming in the ocean on family vacations, attending school dances, and more.

TYPES OF JIA

There are multiple subtypes of JIA:

Systemic JIA, which affects anywhere from 4 to 15 percent of children with JIA. They can have severe joint pain, swelling, and stiffness.

Oligoarticular JIA, which affects almost half of children with JIA and typically affects four or fewer joints with pain, swelling, and stiffness. ("Oligo" means few, and "articular" means joints.) Typically this subtype involves

larger joints (knees, ankles, elbows) in an asymmetric pattern. Oligoarthritis in JIA is further grouped as either "persistent" or "extended." It is unclear whether the extended oligoarticular JIA is the same as seronegative polyarticular JIA. Persistent oligoarticular JIA is when four or fewer joints are affected in the first six months after a child's diagnosis. After six or more months, if five or more joints are affected, it's defined as extended oligoarticular JIA.

Seronegative polyarticular JIA, which affects five or more joints, usually in a symmetric pattern. ("Poly" means many.) About a quarter to a third of children with JIA have this subtype. Kids may have pain, stiffness, and swelling in small joints like the hands, as well as larger joints like knees. "Seronegative" means the child tests negative for rheumatoid factor (RF), which is a protein produced by the immune system that can attack healthy tissue.

Seropositive polyarticular JIA, which affects 10 to 15 percent of children with JIA, is similar to adult rheumatoid arthritis in many ways. Kids with this type of JIA test positive for rheumatoid factor, are usually older, and have more aggressive arthritis.

Juvenile psoriatic arthritis (jPsA), is arthritis that occurs in the context of psoriasis. Psoriasis is an inflammatory skin condition with scaly, red rashes. Your child's fingernails and toenails may be affected too. The arthritis occurs in a minority of patients with psoriasis. While it is usually polyarticular and involves small joints, it seems to follow a different course than polyarticular JIA.

Enthesitis-related JIA (ERA), is a group of conditions that primarily involve the joints of the legs and spine, as well as the entheses, the places where tendons connect to the bones at joints. It affects more boys than girls, primarily in the older age ranges. Many will have the inflammation around the joints (enthesitis) for quite a while before developing actual joint inflammation (arthritis). Some children with enthesitis-related JIA may ultimately develop ankylosing spondylitis (AS) or inflammatory bowel disease (IBD).

Undifferentiated JIA, or a juvenile idiopathic arthritis that just doesn't neatly fit any of the typical disease profiles.

Children with JIA can be at risk for certain complications. This is especially true if a child's disease is not well controlled by medications. Your doctor will give you recommendations for scheduling check-ups provided by other health professionals, like eye exams from an ophthalmologist (eye doctor).

One rare but serious complication of JIA is called **macrophage activation syndrome (MAS)**. About 10 percent of children with systemic JIA (which accounts for 4 to 15 percent of all children with JIA) may develop MAS. It is a life-threatening condition that requires immediate emergency care. If your child has systemic JIA and is at risk for MAS, your pediatric rheumatologist will explain more to you about MAS and any signs you should watch out for so you can get treatment right away.

WHAT'S A TREATMENT PLAN?

When your child is diagnosed with JIA, your pediatric rheumatologist in conjunction with you, your child, and the health care team will create a treatment plan. While prescription medications are at the core of your child's treatment due to the strong evidence supporting their success, drugs are just one part of a successful treatment plan.

Your pediatric rheumatologist, nurses, primary care physician and other doctors, pharmacist, and others on your health care team will review all of your child's prescriptions with you. They will explain how they work and why they were chosen, how and when to give them, what side effects are possible, and any possible interactions that could make it harder for these drugs to work. This may include other medications your child needs to avoid or use only after checking with your doctor first.

Your child's treatment plan has several goals:

- Bring inflammation under control and keep it controlled
- Ease symptoms like pain, swelling, fevers, rashes, or fatigue
- Prevent joint or organ damage
- Prevent complications
- Help your child and your family learn how to better manage JIA
- Assist your child and your family in achieving life goals

Since JIA involves more than just the joints, your child's treatment plan will address more than just symptoms or inflammation. It may include nondrug aspects of treatment, like physical or occupational therapy, a nutritious diet, regular physical activity, good sleep routines, and a positive outlook on life with JIA.

Depending upon your child's individual needs, your pediatric rheumatologist may include other health professionals on your child's health care team. Together, everyone will craft a plan to help your child and family deal with the many aspects of living with a chronic illness. Your child's health care team may include a:

- Primary care physician
- Nutritionist or dietitian
- Physical therapist
- Occupational therapist
- Psychologist or psychiatrist
- Social worker
- Pharmacist
- Educational consultant
- Vocational consultant
- Other physicians (ophthalmologist, orthopedist, or physiatrist)

! Teens with JIA, like their peers, may experiment with alcohol or illegal drugs, like marijuana. Even though your teenager may be officially under the legal drinking age, they may still drink or be offered alcohol at parties or when they hang out with friends (even without you knowing it). Some medications for JIA should not be used with alcohol. Your pediatric rheumatologist can explain the risks and why it's so important to stick to a no-alcohol rule while taking that medication.

PHYSICAL THERAPY AND OCCUPATIONAL THERAPY

Because children with JIA may have joint inflammation that reduces their ability to move around and stay active, physical therapy and/or occupational therapy are important elements of your child's treatment plan.

Physical therapists (PTs) can create a plan to help your child improve mobility, manage joint pain, adapt movements, and get plenty of joint-safe physical activity. They can help with splinting, taping, and pain management, as well as develop home exercise programs to improve your child's abilities and limit any loss of strength, mobility, or function. Occupational therapists (OTs) work with your child to adapt tasks at school or home so they're easier and put less stress on the joints, as well as provide splints and/or adaptive devices, if needed. They can help your child improve fine motor activities, if necessary. An OT can help you work with your child's school staff to ensure that he or she can do schoolwork without limitations, get around the school safely, and acquire any special equipment or tools to make schoolwork easier.

DIETITIANS AND NUTRITIONISTS

New, effective treatments for JIA enable many kids with this disease to grow normally. However, some kids may take medications like steroids that could cause weight gain. Arthritis may make it hurt to move, and children may become fatigued or worn out more easily. Or they just may not feel well on certain days.

Children or adolescents with JIA, like any other young people their age, may be picky eaters. They may enjoy eating junk food or fast food. Teens may try various "diets" to try to lose weight. They may like to eat on the go, choosing processed foods or bagged snacks full of salt and sugar. They may refuse to eat veggies or the healthy dinner you spend so much time preparing. Like all kids, they may spend too much time on their tablets or playing video games, munching on snacks. They're no different than many Americans!

To help your child thrive, a healthy, nutritious diet can be part of the treatment plan too. Fresh foods rich in nutrients are healthy sources of energy. If you need advice on how to shop for and prepare healthy meals for your family, a nutritionist or registered dietitian (RD) may be a good resource for you.

We'll offer some more healthy eating tips for kids and teens later in this guide. Everyone can benefit from a nutritious diet and healthy physical activity, so the whole family can join in. ●

PART FOUR

Treating Your Child's JIA: Current Recommendations

When your child is diagnosed with JIA, you will have all sorts of questions for your doctor:

How can we treat this disease? What treatment options are available, and what's the best option for my child? Is there a cure? Why my child? What are the potential side effects of the treatments? Is he/she going to be crippled? What about my child's brothers or sisters, or future children in our family... will they get JIA too?

Your pediatric rheumatologist can answer these questions and put your mind at ease. Your doctor and nurses can go through their recommendations for your child's treatment plan step by step. While current guidelines provide a general framework for the management of JIA, each child is unique. As your child grows up, his or her treatment plan can change too. So speak up if you don't understand something about your child's treatments, ask questions, and repeat any instructions back to your doctor, so you can be sure you know what's going on.

MEDICAL HISTORY, EXAMS AND TESTS

Your pediatric rheumatologist will order tests for your child to diagnose their JIA and again during regular appointments to see how therapies are working. Tests may show signs of active disease. This helps your doctor determine whether it's time to change therapies, or if the current treatments have your child on the right track.

Medical History and Physical Exam

To develop and, if necessary, change your child's treatment plan, your pediatric rheumatologist will first go through your child's medical history. You'll need to answer questions about any issues your child may have had in the past or recently: unexplained fevers, rashes, or joint pain, and how long these symptoms have been happening.

Because some children with JIA develop symptoms when they're very young — even before they learn to talk or when their speech skills are still developing — it can be hard to know exactly when symptoms may have first appeared. You may have noticed that your child seems to alter simple movements, or change the way they do things, to minimize any discomfort they feel. They are just trying to accomplish the tasks they want to do (whether that's playing with toys or simply moving around the house) with as little pain or discomfort as possible. If you've noticed anything that seems unusual, bring this up during the medical history.

If you have time, **write down your thoughts** about your child's history of symptoms before your first doctor's appointment. Think about a timeline: when did it first seem that something wasn't right? When did your baby first have fevers that didn't seem easy to explain? Writing down your recollections may help you offer your doctor and nurses a clearer picture of when your child's symptoms began and how often they happen.

Your doctor and nurses may also ask you about your family's medical history. This does not mean that your child's JIA is inherited or genetic. Most kids who have JIA do not have a history of JIA in their family. There are some who do have relatives with the disease. But experts don't think it's a disease that parents or grandparents pass on to their descendants.

Active Joint Count (AJC) and Physician Global Assessment

At your regular medical appointments, your child's pediatric rheumatologist will examine your child's joints to see if they are inflamed (red, hot, swollen or tender to the touch, or painful or hard to move), and if your child has any systemic symptoms like fever, rash, or swollen lymph nodes. The results are given a score, such as how many joints are actively inflamed or how many systemic symptoms are evident.

Some scoring tests your pediatric rheumatologist may use include:

JADAS: The Juvenile Arthritis Disease Activity Score. This test is used to help identify which kids may need more aggressive therapy like anti-TNF drugs. **Patient-Parent Global Assessments:** These questionnaires are designed for both you and your child to answer. They can help gauge how much JIA is impacting your child's quality of life or

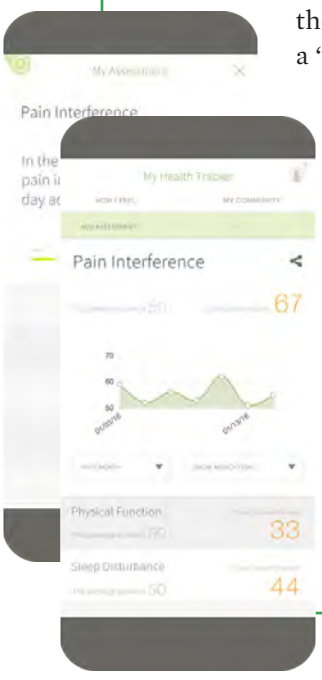
ArthritisPower: Use This App to Keep Track

Do you want a quick, easy way to track your child's ongoing JIA symptoms, treatment, and results? Arthritis Power®, a free app you can download to your smartphone or tablet, allows you to do just that and more.

Arthritis Power is an easy-to-use, interactive app designed for people with arthritis and rheumatic diseases. While children cannot sign up to use Arthritis Power, you can, as a parent or caregiver. You can use Arthritis Power to:

- Log JIA symptoms like pain, stiffness, fatigue, rashes, and fevers;
- Keep track of your child's treatments for JIA, including medications and dosages;
- Note changes, improvements, or issues that your child experiences while on therapy; and
- Regularly update other aspects of your child's ongoing experience with juvenile arthritis

Why should you download and start using ArthritisPower? One, this app can help you keep track of your child's therapy, symptoms, and results, so you can share this data with the pediatric rheumatologist. The information you share can help pediatric rheumatologists and other JIA researchers learn more about this disease, and hopefully, help other kids.



Data drawn from large groups of patients with the same disease or condition — often called a "cohort" — is vital for successful, accurate research efforts. With ArthritisPower, your child's data is secure and never personalized. The information you share can help JIA researchers learn more about this disease, how it affects kids in real life, and how various JIA therapies work to relieve symptoms, control disease activity and prevent joint damage. By using this app, you can also track medication side effects and other important information.

Your participation as a JIA caregiver can help us learn more about this disease, how kids are affected by it, and how therapies can help.

day-to-day routine and well-being.

These scores help your doctor make decisions about which drugs to prescribe first. Over time, these test scores help your doctor track how well your child is doing on current treatments. If the scores signal to your doctor that your child is not doing as well as expected on current therapy, it may be time to adjust the dosing or try something else. That's why these tests are repeated.

Blood Tests

Your child will need blood tests to monitor his or her disease and ongoing treatment. Blood testing can accurately measure levels of substances that are signs of active disease. Blood tests also help identify factors that affect prognosis.

Imaging Tests

For diagnosis and possibly for follow-up exams, your pediatric rheumatologist may also conduct imaging tests. These tests show images of your child's joints, including bones and cartilage. They can show if there is joint damage, or if the arthritis is progressing.

Types of imaging tests include:

- X-ray, both plain radiographs and CT (computed tomography) scans
- Magnetic resonance imaging (MRI)
- Ultrasound, also called sonography
- Nuclear medicine imaging

How to deal with the fear of needles and scary tests: Remember, your child may not need all of these tests every time you go to a doctor's appointment. However, your child will need to get regular finger pricks and needle sticks that may hurt and seem scary.

Some children get anxious or upset when they know it's time for a doctor's

appointment. Many people (not just children) find blood testing, MRI machines, and all other aspects of their medical experiences unpleasant or frightening. Even ultrasound may feel cold or seem scary to a child.

Talk with your child about his or her fears or concerns. If a child is told the truth, and you and other adults in their life are supportive and confident, their experience will be smoother. If you're nervous or anxious, their discomfort may only get worse. So be honest and supportive — and try to project confidence and calm.

Talk with your doctor and nurses about any of your child's concerns. They may be able to offer some tips to you to alleviate your child's anxieties about blood tests or other parts of his or her exams. Some people find it hard to deal with needle sticks while others seem to manage well, so don't get discouraged. You are doing the best you can to handle a very stressful situation for your child (and you). One trick that may help is visualization: Tell your child to think about a happy memory or activity, like playing with the dog or going to the beach. There are many ways to manage stressful situations.

Remember: Your child's health care team is very experienced at working with children with arthritis. They are your best resource for any concerns or questions about your child's treatments. They may be able to put your mind at ease by explaining how these tests work and how often your child will need to have them. They can offer you tips on how to manage your child's fears — and you may find these tips useful for you too! ●

ArthritisPower: Protecting Patients' Privacy

As a parent of a child with JIA, you can use the ArthritisPower app to track your child's symptoms and progress, and share this data with your child's rheumatologist. Children age 18 and younger cannot use ArthritisPower themselves.

ArthritisPower was built by a 501(c)3 nonprofit called the Global Healthy Living Foundation, its arthritis patient community CreakyJoints, and the University of Alabama at Birmingham (UAB). ArthritisPower funding comes primarily from the Patient-Centered Outcomes Research Institute (PCORI), which funds research that offers patients and caregivers the information they need to make important health care decisions. ArthritisPower is led by a governing group of patients called Patient Governors. ArthritisPower exists to improve the lives of people living with joint, bone, and inflammatory skin conditions through patient-centered research.

Patient privacy and security is our number-one priority. ArthritisPower data is stored with Amazon Web Services, which many health care organizations use for everything from basic biomedical research to HIPAA-compliant clinical information systems, including the CDC.

The only people who have access to the ArthritisPower registry and your information are authorized researchers. Our research team will not sell or rent your personal information or personal health information to any other company or organization. We and our research partners are committed to maintaining the confidentiality of your Registry data using industry standards of computer encryption and data security.

If you have any more questions about using ArthritisPower to monitor your child's health, you can contact principal investigator W. Benjamin Nowell, PhD, at bnowell@ghlf.org.

PART FIVE

Medications for JIA

Once your child's diagnosis is confirmed, your pediatric rheumatologist, in concert with you, your child, and your child's health care team, will create a treatment plan. Here are some of the goals your treatment plan is based on:

- Lower disease activity, or levels of active inflammation
- Ease your child's symptoms, like pain, stiffness, swelling, or fevers
- Keep disease activity at a low level over time
- Prevent complications

Your doctor may prescribe one or more medications as initial or "induction" therapy, which is the first phase of treatment. This phase may focus on immediate control of active inflammation and symptoms. After a period of time your doctor may then prescribe maintenance therapy. This means your child's prescriptions and/or dosages may change, and drugs may be added or removed. Some children with JIA may not need to change therapies if their treatment goals are achieved, their disease is under control, and everything looks good. If your child does have ongoing and unacceptable disease activity, your doctor will adjust the treatment plan until the goals are met.

Factors that affect which medications your doctor prescribes and when to start them are:

Active synovitis, or the painful inflammation of the membrane lining the joints. Your doctor will look at how much synovitis your child is experiencing, and may change the treatment plan to help manage it. Which specific joints are affected also makes a difference, not just the number of joints.

Active systemic features. Your doctor will look at your child's overall symptoms, such as rashes, markers of inflammation in the blood, swollen lymph nodes, or signs of liver or spleen inflammation. These are signs that JIA is very active and requires stronger or more targeted therapies. Ask your doctor if there are signs and symptoms you should watch for that indicate active systemic disease.

Quality of life. Your child's quality of life is a central treatment goal. Is he or she able to enjoy activities with other kids or family members? Does your child have energy to participate in school, play, or other activities, or is fatigue making that too hard? Bring up any quality of life issues at your regular appointments.

If you have any questions about your child's specific treatment plan or treatment options, ask your doctor and nurses. While many people look online for information about health, the quality of sources may vary a great deal. You may find information that is incomplete, incorrect, or not applicable to your child. So ask your doctor or nurse before you try to find answers online. If you do see something online that you want to explore, bring your questions (or even a printout of the website or online article) to your health care team.

Your child's pediatrician or primary care physician is a great resource when you're looking for answers to many simple health questions. Your child's pediatrician wants to help your child get better and keep drug side effects at a minimum, so keep this health care team member in the loop. Your pharmacist is also a good resource for treatment-related questions, even those as simple as how to take a pill with food or how to manage milder side effects.

While treatment guidelines are standard suggested recommendations, not every child will need the exact same drug, doses, or overall treatment plan.

When you compare your child's treatment plan with anything you read online, see in magazine articles, or hear about when you speak with other parents, write down the differences you notice. Talk about them with your health care team. They can explain why choices were made to address your child's unique situation. Even if you have more than one child with JIA, one may not be prescribed the same medications or dosage as a sibling with the same disease.

What about side effects?
Every medication has the potential for side effects. Even the most common over-the-counter medication can be problematic for some kids. **Remember the worst outcomes are often the result of damage done because the necessary medications weren't given because of fear of side effects.** These medications can seem scary, because they are. We are asking these treatments to make a big change in the activity of your child's immune system.

Treatment plans are designed by your doctor to balance the potential and expected positive effects of any intervention with possible side effects or "negatives." Most of the time, the outcomes of the disease are worse than possible adverse effects of a particular treatment.

In this section, we'll go over the general groups or types of medications that may be part of your child's overall treatment plan. We'll also discuss the individual drugs in these groups, with their generic and brand names for your information.

Most children will take a combination of treatments to manage their disease, and that often includes not just medications, but physical therapy and occupational therapy as well.

NON-STEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS)

Depending on your child's disease activity as assessed by their doctor, including which joints are affected and how symptoms affect your child's quality of life (physical activity, fatigue, etc.), your doctor may prescribe non-steroidal anti-inflammatory drugs, or NSAIDs.

These drugs may be used in addition to other therapies that modify the disease. They are typically not used alone.

That's because NSAIDs treat inflammation and manage symptoms of JIA, such as painful, swollen, or stiff joints; muscle aches; or fevers. For some children with arthritis, NSAIDs may work well in providing short-term relief or easing the occasional flare of symptoms. But they're not recommended as a stand-alone treatment as they were in the past. This is because they are relatively weak medications. While they help with symptom relief, they do little to address the course of the disease itself.

NSAIDs can be useful as a short-term option for pain relief and to reduce fevers in children with JIA. Several well-known NSAIDs, like ibuprofen or naproxen, are available over the counter and in inexpensive, generic versions. But your child may need a prescription-only NSAID at a higher dose for this short-term relief of pain and other JIA symptoms.

What We Already Know
NSAIDs block fatty acids made by your body called prostaglandins, which are metabolized into inflammatory enzymes called leukotrienes. These acids, such as COX-1 and COX-2, play a role in inflammation and pain. Some NSAIDs block both COX-1 and COX-2, although COX-1 also helps keep your stomach acid under control. There is one NSAID, celecoxib, that blocks only COX-2. It may be gentler on your

child's stomach than other NSAIDs.

Several NSAIDs are approved for use by children:

- Aspirin
- Ibuprofen (Advil®, Motrin®)
- Naproxen sodium (Aleve®)
- Celecoxib (Celebrex®)
- Etodolac (Lodine®)
- Indomethacin (Indocin®)
- Ketorolac (Acuvail®, Acular®)
- Meloxicam (Mobic®)
- Oxaprozin (Daypro®)
- Tolmetin (Tolectin®)

Note: Don't give your child an over-the-counter NSAID if he or she is already taking a prescription NSAID. If the prescription NSAID does not ease your child's pain or fevers, tell your doctors or nurses so your child can try another treatment option, such as acetaminophen (Tylenol®).

Why Is My Child Taking an NSAID?
NSAIDs may provide rapid relief of joint pain or stiffness, as well as fevers. They help with essentially any pain, not just joint pain. While an NSAID may help kids with milder forms of JIA control their symptoms, or may serve as a short-term option for some children with systemic JIA, in most cases they are used in combination with disease-modifying drugs for additional pain and symptom relief. NSAIDs may also be helpful when pain is worse than normal. For example, this drug may help ease a child's aching muscles or joints after a soccer game.

What are the Possible Side Effects of NSAIDs?
NSAIDs are generally safe and easy to tolerate. The most common side effects of taking NSAIDs are stomach pain and bleeding.

Adults who take NSAIDs have an increased risk of serious gastrointestinal effects, like ulcers. However, these side effects are less frequently seen in children who take NSAIDs. Some kids do report stomach pain, nausea, or loss of appetite. To reduce stomach upset, your doctor may prescribe other drugs to take along with the NSAID, like a proton pump inhibitor (Prilosec® or Prevacid®) or H2 blocker (Zantac or Pepcid). Proton pump inhibitors (PPIs) and H2 blockers are also available over-the-counter at your local pharmacy or supermarket.

Other possible NSAID side effects include:

- Increased blood pressure
- Increased risk of heart attack or stroke
- Ringing in the ears
- Lightheadedness or dizziness
- Headaches

- Allergic reactions, or liver and kidney problems (rarely)

If you notice any of these symptoms in your child, get medical care right away:

- Vomiting
- Swollen ankles, hands, or feet from fluid retention
- Black or bloody stool
- Unusual weight gain

There's also a risk of sun sensitivity with some NSAIDs. If your child likes to play outside often, make sure he or she uses sunscreen, protective clothing (shirts with sleeves) or a hat. Be careful on family beach vacations too — everyone should be using sunscreen.

Celecoxib treats arthritis pain as effectively as other NSAIDs, but because it only blocks COX-2 and not COX-1, it may be easier on the stomach. (COX-1 is a prostaglandin that protects the lining of the stomach.)

How to Monitor for NSAID Side Effects
Let your doctor or nurses know if your child complains about heartburn, nausea, stomach pain, or lack of appetite. They may prescribe another medicine to protect her stomach while using NSAIDs, or suggest an over-the-counter antacid.

What Can I Do to Prevent Side Effects?
Here are a few simple tips to help ease NSAID side effects:

- Give your child this medicine with food, such as with meals or at snack time. If your child takes her pills at school, send along an extra snack that's just for eating with medicine.
- Try coated aspirin pills instead of uncoated.
- Don't give your child NSAIDs if they are complaining of stomachache, vomiting, diarrhea, or seem dehydrated.
- Encourage your child to drink a glass of water or milk when taking the pills, not just a few sips.

Topical NSAIDs are another option for sore or stiff joints — usually used to treat "localized" symptoms or those in one specific joint, such as a knee. There are both OTC and prescription topical NSAIDs. They are creams or gels that you rub on the skin where your child's joint is achy or stiff. Talk to your doctor about topical NSAID creams or gels as a treatment option for acute or short-term pain, as these drugs are absorbed through the skin and may not cause stomach upset. They can be a quick, easy way to provide relief for symptoms that doesn't involve swallowing a pill.

If you want to use OTC topical NSAIDs sold at your supermarket or drugstore, such as Aspercreme®, be sure to let your pediatric rheumatologist know. You should always let your doctor know when you use any over-the-counter medications in addition to prescription drugs.

GLUCOCORTICOIDS

Glucocorticoids are also called corticosteroids or "steroids" for short. Glucocorticoids are also used to control

inflammation. They've been around for decades. Cortisone and hydrocortisone were the first steroids used to treat different types of inflammation. Hydrocortisone creams are used to treat mild skin inflammation, and glucocorticoid injections into a single joint (such as the knee) may ease localized pain and inflammation in that spot. Glucocorticoids are pharmacologic variations of the hormones our body's adrenal glands make naturally. Steroids are essential to life, but the issue with taking these synthetic forms of the hormone is how much to take — or the dose — and how long they are taken. While a higher dose of short-term glucocorticoids can get inflammation under control, these drugs can have strong side effects if taken long-term at these doses. So your doctor will try to strike the right balance when it comes to dosage and frequency of these medications.

Children with JIA may take a short-term, high-dose course of stronger glucocorticoids like prednisone, dexamethasone, prednisolone, or methylprednisolone. These come in oral (pills), intravenous (IV) or intra-articular forms (injections). Some children, such as those with oligoarthritis or anyone having a disease flare, may need a short series of intra-articular steroid injections, while fewer children overall may take the oral forms of this drug.

What We Already Know
Glucocorticoids are a version of hormones in our own bodies. These drugs work to control inflammation. They may work very rapidly to calm the inflammation and ease your child's severe symptoms. They can be lifesaving in kids who have inflammation around their heart (pericarditis) or other severe arthritis complications, as well as many other serious health conditions.

While glucocorticoids are powerful drugs that can work quickly, they can have severe side effects and cause long-term problems like weakened, brittle bones. So these drugs are ideally used only for a short time, especially in children.

Your child may need one or a series of liquid glucocorticoid injections in a single inflamed joint. Some kids with JIA might need a short-term dose of either oral (pills) or intravenous (IV) versions of the drug — sometimes given under sedation at the doctor's office. Children with JIA who have severe eye inflammation may also take glucocorticoid eye drops that are given only by prescription.

Tapering: Your child may be given a short "burst" or "pulse" dose of glucocorticoids that's slowly tapered down until the end of this initial therapy period. Tapering is very important when your child takes glucocorticoid pills. Do not let your child stop taking these pills all of a sudden, or skip the last few pills if he or she seems to quickly improve. Tapering means slowly lowering the amount of drug received.

Why is tapering important? Children who take glucocorticoids may become physically dependent on these drugs, and to suddenly stop them could be fatal. Follow your doctor's directions exactly, and taper glucocorticoids as instructed in the prescription.

What Side Effects Are Possible With Glucocorticoids?
Side effects are definitely a concern for any glucocorticoid treatment longer than a few weeks. They're also a strong concern at high doses, so your pediatric rheumatologist will prescribe the lowest possible dose for the shortest possible time for your child's needs. It is also why local dosing, such as joint injections or eye drops, are preferred if possible. Local dosing of steroids may result in fewer adverse effects.

Possible side effects of glucocorticoids include:

- Easier bruising, even from slight bumps
- Bone weakness
- Slower growth
- Weight gain

- Fluid retention
- Irritability or mood swings
- Acne
- Altered blood sugar and fat metabolism

Long-term side effects possible with glucocorticoid use include glucocorticoid-induced osteoporosis, weakened muscles, weakened immune system, glaucoma, cataracts, and diabetes.

Call your doctor's office or go to the emergency room right away if you notice any of these signs of a serious reaction while your child is taking glucocorticoids:

- If your child has a fever
- If your child says it burns or hurts during urination
- If your child's stool looks bloody, black, or like tar
- If your child vomits blood, something that looks like coffee grounds, or otherwise seems unwell

Serious reactions to glucocorticoid injections or IV treatments are rare, but possible. Call your doctor's office or seek emergency treatment right away if you notice any these signs of an allergic reaction in your child:

- Redness, itching, or swelling around the injection site on the skin
- Shortness of breath or wheezing
- Swollen face, lips, eyelids, mouth, or tongue
- Sudden hives on the skin
- Flushed face
- Seizures
- Tight feeling in the chest

How to Monitor for Possible Side Effects of Glucocorticoids

Let your doctor or nurses know if your child has any of the side effects from a short-term dose of glucocorticoids. Remember: These effects should not last long, and may ease significantly when your child's dose tapers down. Some kids may not have any noticeable side effects.

If your child is taking oral glucocorticoids, give the dose as prescribed at the same time each day. Your doctor may advise taking this drug in the mornings (although always go by what's in your child's treatment plan), as it may help your child tolerate the drug more easily and prevent side effects. Taking steroids in the morning mimics the body's normal cortisol cycle. If your child has any nausea or stomach upset after taking the pills, giving them with food, bread, or milk may help.

With these drugs it is important that your child takes the medicine even if they are feeling unwell. If they cannot take the medicine they need to be seen in the doctor's office or emergency room.

If your child is unable to swallow her pills, talk to your doctor before cutting or grinding the pills. There may be other options, including liquid forms, an IV, or injections of steroids. Your pharmacist may be able to flavor the medication to minimize the metallic taste. Again, even if your child has side effects, don't suddenly stop the

glucocorticoid treatment. Your child should take the whole treatment course and taper off the drug.

If you notice any of the signs of a possible severe infection, drug reaction, or allergic reaction that are listed above, get medical care for your child right away. Ask your nurses or the pharmacist if you're unsure what these signs may look like or which ones may be very serious warnings.

DISEASE-MODIFYING ANTI-RHEUMATIC DRUGS (DMARDS): CONVENTIONAL OR NON-BIOLOGIC

For many kids with JIA, glucocorticoids and NSAIDs are only short-term options to control a flare of inflammation or to ease symptoms. Most children need to take a conventional disease-modifying anti-rheumatic drug (or cDMARD), either on its own or in combination with other treatments.

DMARDs control inflammation and slow or prevent disease progression and damage.

A longtime mainstay of juvenile arthritis treatment, cDMARDs do more than ease JIA symptoms. They modulate your child's immune system response to slow and ideally stop the causes of inflammation at the source. These drugs have been approved for many years, and they are well studied for safety and effectiveness in kids.

Methotrexate (Rheumatrex®, Trexall®, Otrexup®, Rasuvo®) leflunomide (Arava®), sulfasalazine (Azulfidine®) and hydroxychloroquine (Plaquenil®) are the most common cDMARDs prescribed to treat JIA.

While cDMARDs do help many children modulate their disease, control JIA inflammation and, thereby, reduce their symptoms, they also spare these children the need to take glucocorticoids for too long. So these drugs can help your child avoid the severe side effects of steroids. They play a critical role in the treatment of JIA.

A cDMARD alone may not be that effective at modulating disease activity, so these drugs are often used in combination with other treatments.

Methotrexate (Rheumatrex®, Trexall®, Otrexup®, Rasuvo®) Methotrexate is the most common DMARD used alone or in combination with more targeted therapies. It's used to control inflammation, modulate disease activity, prevent joint and organ damage, and ease arthritis symptoms.

What We Already Know
Methotrexate works by blocking certain enzymes in your child's body that contribute to inflammation and disease. While these processes may ease inflammation, they may cause side effects too. Dosing affects how well methotrexate will work and its likelihood of causing side effects.

Your child will take methotrexate once a week as either a pill or injection under the skin. While pills may be less scary than a needle, talk with your pediatric rheumatologist about which version may be more effective for your child. Injected methotrexate tends to be more effective at modulating disease activity and also may have fewer adverse effects.

Methotrexate's effects typically start to be noticed within about three to six weeks. However, it may take up to three months for you to notice the full effects of the drug in your child.

What are the possible side effects of methotrexate?
Not every child experiences side effects from methotrexate. Those who do have them may find that they ease with time. Side effects are more likely to occur at higher doses.

Here are some possible methotrexate side effects:

- Nausea, vomiting, stomach upset, queasiness
- Mouth sores
- Breathing problems (very rare in kids)
- Hair loss (usually temporary)
- Feeling foggy
- Rarely, kids who take methotrexate can have abnormal liver enzymes (liver abnormalities) or low white-blood cell counts, but regular blood tests can keep track of these levels
- Also rarely, liver cirrhosis
- Photosensitivity (sensitivity to sunlight)

Note on drinking: Methotrexate can affect the liver, and rarely, cause liver cirrhosis. Your child should not drink alcohol while taking methotrexate. If you have a teenager who is taking methotrexate, make sure you sit down and talk about the dangers of drinking alcohol while they are on this drug. Because methotrexate affects liver enzymes, it should not be mixed with alcohol. If you think your teen is sneaking alcohol or drinking with friends without telling you, talk with your pediatric rheumatologist so you can all discuss it together at your regular appointments.

Remember: Even "good kids" may want to drink with other kids to fit in during middle or high school, so don't assume that your child doesn't drink alcohol. Let them know that they can have fun without drinking.

How Can Methotrexate Side Effects Be Managed?

Folic acid supplements may help your child ease many methotrexate side effects. Methotrexate lowers the metabolic activity of some cells, including the enzyme that plays a role in the metabolism of folic acid. Research shows that taking folic acid on the same day as methotrexate does not reduce the methotrexate's effectiveness, but your doctor may want to have a conversation about a folic acid schedule. Regardless of when your child takes folic acid, it may help reduce side effects. Folic or folicinic acid supplements may be prescribed by your doctor ahead of time to prevent methotrexate's side effects.

If regular folic acid doesn't help, you may try another type called methylated folic acid. Talk to your doctor about methylated folic acid if your child still gets mouth ulcers, hair loss, or nausea from methotrexate even while taking a folic acid supplement.

Are There Any Other Risks I Should Know About?

Methotrexate can cause severe birth defects if one is pregnant while taking it. Therefore, people who take methotrexate should not get pregnant. While this may not be a concern for parents of younger children with JIA, if your child is a teenager, talk about these serious risks for both males and females who take methotrexate.

It is important to talk about all the risks involved in unplanned pregnancies, not just those from being pregnant while taking methotrexate. Having JIA places potential risks on both the mother and the baby, making it even more important to use birth control if engaging in sexual activity. While this may be an uncomfortable or sensitive topic for you to bring up with your teen, it's important that you have "the talk." Ask your child's physicians and nurses to be part of the conversation if you feel it's appropriate.

In addition, certain antibiotics called "sulfa" drugs (such as Bactrim®) should not be taken by people who are on methotrexate. Children should not get any live vaccines while they take methotrexate. This includes chickenpox and the measles, mumps, and rubella (MMR) vaccines. You can schedule these vaccines for your child before

Vaccinations: What You Need to Know

Your child's prescription medication may carry a warning about avoiding live vaccines. Your pediatric rheumatologist and nurses can give you detailed information about which vaccines or immunizations are safe for your child to receive while he or she is taking these medications.

Don't vaccines protect your child from infectious diseases? Yes, but live vaccines use actual viruses and bacteria to help your child develop immunity against the particular infections. So your child may get sick if they get these live vaccines while they take medication that suppresses their immune system. They also may not respond as well to the vaccine.

Which vaccines are live? There are a few, and your child may have already had some of these in the past:

- Smallpox
- Measles, mumps, and rubella (MMR)
- Chickenpox
- Rotavirus
- Zoster
- Yellow fever
- Influenza mist (nasal spray only)

Your health care professionals will go over vaccinations and how to schedule these for your child. Let them know which vaccines he or she has already taken.

Some vaccines are OK for your child to have while on immunosuppressant drugs. Killed vaccines use a version of the virus or bacteria that is safe. The regular flu shot is one example, as are the HPV and HBV vaccines.

Herd immunity: You may have heard of herd immunity. That's the immunity of a large population to an infectious disease. When everyone gets the recommended vaccines, there is more effective resistance overall to the infectious diseases involved. That's why it is important for not just your child, but your whole family and your child's friends and classmates to be fully immunized. When some families refuse to get vaccinations for any reason (such as unproven fears of side effects), it can affect herd immunity and put everyone at risk.

If your child has not had a chickenpox or MMR vaccine yet, talk with your pediatric rheumatologist about how your child may be safely vaccinated against childhood illnesses. Your child may be able to get vaccinated before starting JIA therapy. Your pediatric rheumatologist or primary care doctor will go over the necessary vaccinations and immunizations that your child needs to have, and let you know which vaccinations to avoid while your child is on therapy for JIA.

Don't give your child any vaccines or shots without talking with your pediatric rheumatologist first. Your doctor can also advise you about how to inform schools or summer camps about your child's vaccination status and what to monitor while your child is there.

starting this drug. Talk with your child's physicians about scheduling your child's vaccinations.

Because methotrexate affects the immune system's activity, your child could be more susceptible to infections. Let your doctor know if your child shows any signs of infection, like sore throat, fevers, muscle aches, chills, or runny nose. If your child has been around other children with flu or other infectious diseases, let your doctor know. Monitor your child with JIA more closely and let your doctor know if any symptoms occur.

Methotrexate can make your child's skin more sensitive to sunlight or sunburns, so apply sunscreen (SPF of 15 or higher) to your child's exposed skin before he or she goes outside to play or exercise. Encourage your child to wear shirts with long sleeves or lightweight, long exercise pants. Hats and sunglasses are also a good idea for outdoor activities or at the beach.

LEFLUNOMIDE (ARAVA®)

Leflunomide is another cDMARD used by some kids with JIA. It is administered by itself as a first treatment option, in combination with other drugs, or as maintenance therapy.

Your child may need to take leflunomide for around one to three weeks before JIA symptoms start to improve. You may not see the drug's full effects for six to 12 weeks.

What We Already Know

Leflunomide interferes with DNA, or the building blocks of all living cells, by limiting them from replicating. Since cells of the immune system replicate faster than most other cells in the body, leflunomide has a greater effect on the immune system than on other tissues. By slowing the activity of the cells driving inflammation, leflunomide can help reduce your child's JIA inflammation.

Leflunomide comes in a pill that your child will swallow once a day. Before starting leflunomide, your child will have blood tests to evaluate their liver function and blood cell counts. Regular blood tests will be done to ensure that your child is tolerating the drug well.

What Are the Possible Side Effects of Leflunomide (Arava®)?

Diarrhea and nausea are the most common side effects for children taking leflunomide. More rarely, kids may experience rashes, high blood pressure, or thinning hair. Though it's rare, they may also have abnormal liver function test results or abnormal platelet levels. Platelets are blood cells that help the blood clot after a cut or injury.

Just as with methotrexate, kids who take leflunomide should not receive any live vaccines, such as the MMR or chickenpox vaccines. Talk with your pediatric rheumatologist about how to safely vaccinate your child. In addition, leflunomide may make it harder for your child to fight off infections. If you notice signs of infection, like fever, chills, sore throat, or cough, let your doctor know right away.

Like methotrexate, leflunomide should also never be mixed with alcohol. Talk with your teen about these risks and how to handle any social situations when they might be offered alcohol. Leflunomide may also cause birth defects, so teens who take this drug should use birth control and take precautions to avoid unplanned pregnancy.

How Can I Help My Child Manage Side Effects of Leflunomide (Arava®)?
Diarrhea is probably the most common side effect of leflunomide. It may be unpleasant for your child (and you, if you have to clean up any accidents), and it also may be embarrassing for your child if it causes emergency bathroom runs at school or at friends' houses.

Your child may be able to take an anti-diarrhea medication with leflunomide to ease this side effect, which may also lessen over time. If not, your child's doctor may be able to adjust the dose.

SULFASALAZINE (AZULFIDINE®)

Sulfasalazine (Azulfidine®) contains a mix of salicylate, the active ingredient in aspirin (which was the original nonsteroidal anti-inflammatory medication), and sulfa, an antibiotic.

What We Already Know
Sulfasalazine could be viewed as an antibiotic/anti-inflammatory drug, but it's grouped with DMARDs. That's because sulfasalazine does have a modifying effect on your child's immune system. It can ease joint pain, swelling, and stiffness, and it can also slow down or prevent damage to your child's joints. Sulfasalazine may help preserve your child's joint mobility and joint function over time.

Your child can take sulfasalazine in either liquid or pill form. For kids who are either too young or just can't swallow pills, it's good to have two options. Sulfasalazine is given by mouth twice a day.

As with other DMARDs, your child will have blood tests to check liver function and blood cell levels before starting sulfasalazine. Regular blood tests will be done to watch for any signs of drug side effects on the liver or blood cells.

What Are the Possible Side Effects of Sulfasalazine (Azulfidine®)?
The most common side effects children have when taking sulfasalazine are stomach upset, nausea, vomiting, dizziness, headaches, skin rashes, and sensitivity to sunlight.

Rarely, sulfasalazine may cause abnormal liver function or abnormal levels of white or red blood cells and platelets. Your child will need blood tests to watch for these side effects.

If your child is allergic to sulfa drugs (often used as antibiotics), he or she should not take sulfasalazine. Talk with your pediatric rheumatologist if you're not sure about this or what drugs are included in this category. Do not take other NSAIDs (such as OTC pain relievers) with sulfasalazine, since the drug is already composed of an NSAID.

If your child develops a more severe rash, sunburn, skin discoloration, or skin reaction to the sun, stop the medication and immediately inform your doctor.

Stevens-Johnson syndrome is a serious side effect possible with sulfasalazine. It could be life-threatening, so watch

out for the signs and seek medical care right away if you notice them. The first signs may resemble the flu: fever, cough, sore throat, fatigue, and burning or sore eyes. A few days later, your child may develop a painful skin rash (red or purple) that spreads across the body, and blistering around the mouth, nose, or eyes. Seek emergency treatment right away if you notice the signs of Stevens-Johnson syndrome.

Sulfasalazine may also increase your child's risk of getting an infection or lower the ability to fight one off. If you notice the signs of infection, let your doctor know.

How Can I Manage the Side Effects of Sulfasalazine (Azulfidine®)?
If your child has stomach upset, nausea, or vomiting with sulfasalazine, coated pills may be less harsh on the stomach, and your doctor may prescribe them first. If your child's pills are not coated, ask your doctor or pharmacist if these are available.

Because sulfasalazine can make your child's skin more sensitive to sunlight or sunburns, apply sunscreen (SPF of 15 or higher) to your child's exposed skin before he or she goes outside to play or exercise. Encourage your child to wear shirts with long sleeves or lightweight, long exercise pants. Hats are also a good idea for outdoor activities or at the beach.

Note on sunscreen use: Sunscreen can wear off or wash off if your child goes swimming. Reapply sunscreen every 60 to 90 minutes when your child is playing or socializing outdoors. Use SPF-treated clothing if possible, and minimize the time outside in the middle of the day when the sunlight is strongest and most direct. Even when your child feels cool — such as when swimming in the pool, lake or ocean, or playing in snow in winter — there's a lot of reflected sunlight that could cause sunburn. So use sunscreen liberally, reapply often, and cover up.

HYDROXYCHLOROQUINE (PLAQUENIL®)

Some children with JIA may also take a drug called hydroxychloroquine. This medication was originally used to treat malaria, but it has been found to have significant anti-inflammatory effects also useful in treating JIA.

Hydroxychloroquine seems to help control joint pain and swelling, prevent joint damage, and even lower your child's risk of long-term disability due to damaged joints.

What We Already Know
Hydroxychloroquine may disrupt the communication between different cells in your immune system. By doing so, it helps to slow down these overactive immune processes that cause inflammation and damage.

Hydroxychloroquine is given as a pill once a day, along with food. Your child can take it at mealtime or with a snack. Your child may have improved symptoms with hydroxychloroquine after a few weeks. It may take a few months for the drug's full effects to develop.

Your child will need to have regular blood tests and eye exams to make sure that hydroxychloroquine isn't having any negative effects.

What Are the Possible Side Effects of Hydroxychloroquine (Plaquenil®)?
Side effects of hydroxychloroquine are somewhat rare, but they can include:

- Inflammation of the retina at the back of the eye, which may cause blind spots or difficulty judging colors
- Stomach upset

- Nausea
- Rashes
- Sun sensitivity to the skin
- Bleaching hair
- Low blood cell counts (these will show on those regular blood tests)

Hydroxychloroquine can affect your child's eyes or vision, but the ophthalmologist will monitor for any vision side effects at your child's regular eye exams. Some doctors recommend regular eye exams every three months; others recommend every six months.

How Can I Manage the Side Effects of Hydroxychloroquine (Plaquenil®)?
Most kids will not have side effects from hydroxychloroquine. If your child does have nausea or stomach upset, taking the pill with food may help. Schedule "pill taking" time with family meals or afternoon snacks.

Hydroxychloroquine can also make your child's hair and skin more sun sensitive. To protect your child's skin or hair from the sun, use sunscreen and protective clothing and hats. Kids who love to play outside or take part in outdoor sports should use these precautions to avoid sunburns. These tips are a good idea for everyone in the family.

MORE TARGETED THERAPY: BIOLOGIC DMARDS (BDMARDS) FOR JIA

Methotrexate and other cDMARDs may not work sufficiently well enough for some kids with JIA. Some children may need more targeted treatments, such as biologic DMARDs or bDMARDs.

Why aren't cDMARDs sufficient for some kids? One reason is that JIA involves many different cells of the immune system interacting in various combinations and permutations. So they need drugs that target those particular cells, and their interactions.

For years, researchers worked to determine the exact proteins, or cytokines, and processes that caused inflammation in different kids with JIA. They discovered that there were quite a few different molecules that could play a role in this disease, and then developed targeted drugs to block them. Research has also shown that the various cells and proteins interact in many ways, so that blocking them is more complex than we once thought. The trick is to block these immune system activities just enough to control the disease, but not so much as to create more problems. It's all very, very complicated, as you would expect.

These drugs target particular sources of inflammation in JIA, such as:

- Tumor necrosis factor (TNF)
- Interleukin-1 (IL-1)
- Interleukin-6 (IL-6)
- Certain B cells, a type of white blood cell
- Certain T cells, another type of white blood cell

Infection Risk: Tips to Fight Off Dangerous Bugs

DMARDs of all kinds modulate the immune system, which is an essential and necessary part of how these drugs work. But they may lower your child's ability to fight off certain infections. Is there anything you can do to help prevent infections? Here are some common sense tips to keep in mind:

Wash hands often. You and your child should lather up hands with soap and water regularly, especially before and after play dates, school, or visits with other kids who may be sick.

Keep antibacterial rubs on hand. Alcohol-based gels or lotions like Purell® or other brands can be used for quick hand clean ups. Keep a small bottle in your purse, backpack, diaper bag, or the storage compartment in your car.

Keep toys clean. Toddlers and young children love to stick toys in their mouth, so make sure you clean toys as often as you can. Keep wipes handy for a quick clean up after a toy hits the floor.

Watch out for sharing opportunities. Try not to let your child share pacifiers, utensils, cups, or toys with another child who has an infection.

Keep up with flu vaccinations. Your child can have some vaccines while taking biologic drugs. Flu shots (excluding the nasal mist form) are "killed" vaccines, not "live" vaccines. Your pediatric rheumatologist and nurses can tell you which vaccines are OK to have. Make sure you and your family members are vaccinated for the flu and other recommended vaccines.

Avoid sick people as possible. It's not always easy to avoid people in your daily life who have the flu, bronchitis, or stomach viruses. You can run into them everywhere... even in your own home. If the mom or dad of your child's playdate buddy calls to tell you their child has a bad cough or signs of flu, reschedule! If grandma has a chest cough, it may be better if your child sees her another time. Listen for any

If your child starts using any DMARD, schedule any recommended live vaccinations, such as chickenpox and measles, mumps, rubella (MMR) first, if you can. Talk with your pediatric rheumatologist and your child's other doctors about vaccinations your child should have.

Don't worry when your doctor orders a tuberculosis (Tb) test:
Biologic drugs work by suppressing or slowing down a child's immune system. As a result, anyone who takes a biologic may be vulnerable to getting infections.

Tuberculosis (Tb) is one infection that is a potential worry for anyone who takes a biologic drug. Tb is a serious bacterial infection that primarily affects the lungs, but can also affect many other organs. While Tb was a major health concern and leading cause of death before antibiotics were available, most people in the U.S. think that Tb is a thing of the past. However, the disease is on the rise again. In some parts of the world, people are infected with a drug-resistant form of Tb. Even in some parts of the U.S., Tb is endemic, or more commonly seen. It is also still common in many other countries, so you need to be careful if you travel to these countries to visit family or on vacations.

The part of your child's immune system that is involved in causing arthritis, and that is modulated by these bDMARD medications, is not the same part of the immune system involved in fighting Tb or other infections. But we don't want to risk the reactivation of Tb by starting these medications if your child already has Tb. That's why the test is done. Tb is screened with either a blood or skin test.

In most cases, you'll get your bDMARDs shipped to your home from a specialty pharmacy. Biologic DMARDs are made from living material, so it's important to refrigerate, store, or handle them as prescribed. Follow any instructions on the packaging about how to store or mix them if they require it.

If you have any questions about which targeted therapy may be right for your child, or how to handle

updates from your child's school, daycare or camp about any outbreaks of infections.

Be aware of infection risks. Most people don't think about tuberculosis, a serious bacterial infection, or specific viral or fungal infections. But these can be dangerous for any child who is taking an immunosuppressant drug for JIA. So be aware of any risks of exposure, even if they're unlikely to happen. If any of your family members or visitors to your home have had tuberculosis or visited a region where Tb or other infections are endemic, contact your doctor's office. This goes for fungal infections too. Some parts of the U.S. (the Ohio and Mississippi River Valleys, the Southwest) are more prone to fungal infection outbreaks. Any family member or visitor who has been in a U.S. prison recently may also have been exposed to Tb, so use caution. Shingles is a reactivation of the chickenpox virus and is another infection to avoid. Older people are at highest risk of developing shingles.

Handle food safely. Food-borne illnesses are common and can be severe. Spoiled food may not always smell, look or taste bad just yet. So follow all expiration dates and handling instructions on foods, from meats to veggies to packaged foods. Cook meats and poultry to the recommended temperature (your recipe or packaging should have this information, or look online). If something doesn't seem fresh, toss it out! It's not worth the risk. Wash all foods properly.

the drug or give it to your child, talk with your pediatric rheumatologist, your nurses, and your pharmacist. While they'll provide detailed information for you along with your child's prescription, they are also a great resource for you as a parent. Speak up, ask questions, and let them know if you have any concerns.

TNF INHIBITORS

TNF inhibitors are the first class of biologic DMARDs used to treat JIA. They block a cytokine (which is a protein secreted by the immune system that has an effect on other cells) called tumor necrosis factor alpha, or TNF. These drugs revolutionized the treatment of JIA and other rheumatic diseases when they first came on the scene.

These therapies not only help many kids with JIA reduce their inflammation and symptoms, but they prevent joint and organ damage, prevent disability, and preserve joint function because they reduce inflammation and the disease activity. These medications have literally changed the course of JIA and other inflammatory diseases.

ETANERCEPT (ENBREL®)

Etanercept is a TNF inhibitor that can reduce JIA disease activity and ease arthritis symptoms. Etanercept is specifically approved for kids with moderate to severe polyarticular JIA who are age two or older.

What We Already Know

Etanercept is given as an injection under the skin once or twice a week. The medicine comes in prefilled syringes, or in vials of powder that you mix up to inject before use. The medicine is shipped to you by the pharmacy. Follow all storage instructions carefully, as this medicine is sensitive to temperature or shaking. This drug must be properly stored as directed on the prescription instructions in order to be effective.

Etanercept also comes in prefilled auto-injection devices, which are more like pens that you click and then inject into the fleshy part of your child's thigh or abdomen. Some people find these pens easier to use than syringes, but it's up to you and your child.

Your pediatric rheumatology nurse can show you how to properly mix powdered etanercept and fill up syringes, if you use the drug in that form, and how to inject your child under the skin. Once you get the hang of

it, you will be able to give your child injections with no problems. Teens and pre-teens with JIA may also learn to inject themselves.

Etanercept's recommended dosage for kids with JIA is 0.8 mg per kg of body weight once per week, with a maximum dose of 50 mg per week. Your doctor may prescribe a higher dose to control your child's disease.

What Are the Possible Side Effects of Etanercept (Enbrel®)?
Infections and injection site reactions, such as redness, local swelling, burning, and itching where the needle goes in, are the most common side effects associated with etanercept. More rarely, kids may have side effects such as skin rashes or allergic reactions. Signs of allergic reaction include hives or skin rashes; swollen lips, mouth or face; and trouble breathing or wheezing. Seek emergency treatment if you notice these signs in your child.

Other very rare adverse events associated with etanercept use include neurologic problems such as demyelinating disorders and seizures, low blood counts, autoimmune disease such as systemic lupus or hepatitis, and increased risk of some malignancies (cancers). There is also a risk that a child may develop antibodies to the drug, but the consequences of this are unknown. Ask your pediatric rheumatologist about possible risks for using etanercept, and how the many benefits may outweigh the risks.

Kids should not be given any live vaccines while using etanercept. Chickenpox and measles, mumps, and rubella (MMR) vaccines are "live" and should be avoided. If possible, pediatric patients should be brought up to date with all vaccines before they start etanercept. Ask your doctor or nurse if you're unsure which vaccines are live and which ones are safe.

What Can I Do to Manage the Side Effects of Etanercept (Enbrel®)?
Watch for any signs of infection or any of the other rarer side effects in your child. Use precautions to prevent infections such as the flu, and let your doctor know right away if your child has the signs of an infection.

ADALIMUMAB (HUMIRA®)

Adalimumab is another TNF inhibitor. It is another type of living material (called a monoclonal antibody) that works to control your child's disease activity. It eases JIA symptoms and prevents joint and organ damage and disability.

Adalimumab is approved for treatment in kids with moderate to severe polyarticular JIA who are age two or older.

What We Already Know

Adalimumab is given as an injection under the skin once every two weeks. It comes in a prefilled syringe or auto-injection pen.

Follow any instructions on the packaging for proper storage of these medicines. As they are proteins made from living material, they need to stay at the right temperature to remain fresh.

Adalimumab dosage is based on your child's body weight. Kids who weigh between 10 kg and 15 kg take 10 mg every other week. Kids who weigh between 15 kg and 30 kg take 20 mg every other week. Kids who weigh 30 kg or more take 40 mg every other week.

As with etanercept, you can give your child his or her adalimumab injections at home. Your nurse will show you how to properly give the injections. Ask any questions if you're unsure.

What Are the Possible Side Effects of Adalimumab (Humira®)?
Injection site reaction — redness, burning, or itching around the needle site on the skin — is the most common side effect of adalimumab. Ask your doctor about tips to help reduce this side effect.

More rarely, kids may have side effects like skin rashes or flu-like symptoms. As with any drug, allergic reactions are possible. Signs include swollen lips, mouth, or face; hives or skin rashes; trouble breathing or wheezing; or dizziness. Seek emergency treatment if you notice these signs in your child.

Other rare side effects of adalimumab use include low blood cell counts, increased risk of infections, and increased risk of some malignancies (cancers), although recent research suggests otherwise. Ask your pediatric rheumatologist about possible risks for using this drug, and how the many benefits may outweigh the risks.

Kids should not take any live vaccines while using adalimumab. Ask your doctor or nurse if you're unsure which vaccines are live and which ones are safe. Chickenpox and measles, mumps, and rubella (MMR) vaccines are "live" and should be avoided.

What Can I Do to Manage the Side Effects of Adalimumab (Humira®)?
Watch for any signs of infection in your child. Use precautions to prevent infections like the flu, and let your doctor know right away if your child has the signs of an infection.

INFLIXIMAB (REMICADE®)

Infliximab is a TNF inhibitor. It is not specifically approved for kids with JIA, but your pediatric rheumatologist may prescribe it off-label. This drug is used for many children with JIA, even though JIA is not an FDA-approved indication for the drug at this time.

What We Already Know
Infliximab is prescribed to reduce inflammation and ease symptoms like joint pain or swelling. Like other TNF inhibitors, infliximab may help prevent joint and organ damage.

This drug is given as an infusion, or via an intravenous (IV) drip at your doctor's office, a special infusion clinic or center, or your local hospital. Your child will lie down and relax while a nurse inserts the needle into a vein or port and supervises the treatment. Infliximab dosage is based on body weight, and your child will typically receive these infusions once every one to two months.

What Are the Possible Side Effects of Infliximab (Remicade®)?

Infusion-related reaction is the most common side effect of infliximab. Signs include hives or skin rashes, trouble breathing, nausea, chest or stomach pain, and changes in blood pressure. These reactions tend to happen during or shortly after an infusion.

More rarely, kids may have side effects such as flu-like symptoms. As with any drug, allergic reactions are possible. Signs include swollen lips, mouth, or face; hives or skin rashes; trouble breathing or wheezing; or dizziness. Seek emergency treatment if you notice these signs in your child.

Other rare side effects of infliximab include low blood cell counts and increased risk of infections. There's also a rare risk that a child may develop autoantibodies that interfere with the drug's ability to work. Some experts believe that adding methotrexate can help reduce the development of these autoantibodies. These are very rare risks. Ask your pediatric rheumatologist about possible risks of using this drug, and how the many benefits may outweigh the risks.

Kids should not receive any live vaccines while using infliximab. Ask your doctor or nurse if you're unsure which vaccines are live and which ones are safe. Chickenpox and measles, mumps, and rubella (MMR) vaccines are "live" and should be avoided.

How Can I Manage the Side Effects of Infliximab (Remicade®)?
To help prevent serious infusion-related reactions, your child may receive a dose of acetaminophen (Children's Tylenol®) or diphenhydramine (Benadryl®) before your infusion appointment.

OTHER BIOLOGIC DMARDS

TNF-inhibitors are just one group of biologic DMARDs that may be prescribed to treat your child's JIA. In this section, we'll explore the many other biologic DMARDs used to manage JIA, including drugs that inhibit interleukins, T cells, and B cells.

ANAKINRA (KINERET®)

Anakinra is not a TNF inhibitor. It's another type of biologic drug that targets the protein interleukin-1 (IL-1). It's called a "recombinant" (or a revised combination of the genetic material) version of the protein. It inhibits the body's production of IL-1. Anakinra may sometimes be used as the first therapy in kids with active systemic features.

What We Already Know
Anakinra is not currently approved by the U.S. Food and Drug Administration (FDA) for JIA, but your pediatric rheumatologist may choose to prescribe it off-label.

Anakinra dosage is based on your child's current body weight. Children typically start with a dose of 1-2 mg/kg of body weight each day. Anakinra is given as an injection or shot. While your doctor or nurse may give your child the first injection in the clinic, you'll give your child these shots afterward on your own. Older kids may learn to give themselves injections with your supervision.

Anakinra also needs to be stored at the right temperature to be kept fresh and to stay active. Store the prefilled syringes in your refrigerator. You'll take each syringe out and let it warm to at least room temperature before you give your child a daily injection. (Tip: Warm the syringe under your arm or similar warm body area to have it reach closer to body temperature, as that decreases the injection discomfort.) Usually, you give an anakinra injection in the fleshy

part of the front of the thigh or abdomen. It's a good idea to rotate to different spots each time. Ask your child's nurses if you're unsure how to give these injections properly, or if you just want a few helpful tips.

If you have a spouse or partner, or another family member or friend who helps you care for your child, bring them along to the clinic when you learn how to give your child the injections. They may need to step in and administer the shot if you're unavailable on certain days.

This is true for all injections. If no one is available, your child's school nurse or a nurse at your primary care doctor's office can do it. Some insurers will cover a home nurse to administer the injection until a family member is sufficiently comfortable doing it, so it may be worthwhile to ask your insurer if this would be covered.

Why Is My Child Taking Anakinra (Kineret®)?
By blocking IL-1, anakinra helps to quickly control inflammation and relieve symptoms. While it may take from four to six weeks for anakinra to relieve symptoms in adults, it may work much faster in children with JIA. Some kids may even experience symptom relief within hours of their first dose, because IL-1 and/or IL-6 are the primary drivers of disease activity in systemic-onset JIA.

What Are the Possible Side Effects of Anakinra (Kineret®)?
Anakinra's most common side effect is an injection site reaction. This may look like redness, pain, itching, or a slight rash around the area where the needle goes in. These are less common in kids than in adults who take anakinra.

Less common side effects include bruising or bleeding, but these often go away after a week or two. Headaches, low white blood cell counts, vomiting, diarrhea, joint pain, fever, flu-like feelings, and sore throat or runny nose are much rarer, but possible. These symptoms are very much the same as the symptoms of an infection.

Anakinra and other biologics modulate the immune system's activity. So your child may be at increased risk of infections. Fevers, flu-like feelings, diarrhea, and sore throats may be signs of an infection. Talk with your child's doctors about how to know the signs of infection and when to seek care right away.

It's rare, but anakinra may also cause your child to have an allergic reaction (as any medication can). Signs include swollen lips, mouth, tongue, or face; wheezing or shortness of breath; itching or rash on the skin; feeling dizzy or fainting; unexplained sweating; rapid heartbeat; or redness and swelling around the site of the injection. While your child is taking anakinra, he or she should not take any live vaccines. Work with your child's physicians to set up a schedule for vaccinations.

How to Monitor for Side Effects of Anakinra (Kineret®)
If you think your child has an infection based on the signs and symptoms listed above, call your doctor's office right away or go to the emergency room. Your child may need immediate treatment. Because anakinra suppressed your child's immune system, infection risk goes up. So don't take any chances. Ask your pediatric rheumatologist or nurses how to spot the signs of a serious infection.

Watch for those signs of a possible allergic reaction. Call your child's doctor's office or go to the emergency room if you think your child is having an allergic reaction to anakinra or any other drug.

CANAKINUMAB (ILARIS®)

Canakinumab is another biologic DMARD that's called a human monoclonal antibody. It's a clone of a natural antibody that binds to certain cells. It targets the cytokine interleukin-1-beta (IL-1-beta). It is FDA-approved and

indicated for use in kids with systemic JIA who are age two or older.

Canakinumab may be either an initial treatment option or used after another treatment has not worked well. It may also be used as maintenance therapy if your child has active disease. It may be given alone or in combination with other drugs.

What We Already Know
Canakinumab blocks IL-1-beta, a cytokine, or protein, that can play a role in disease activity in JIA. IL-1-beta can cause inflammation and joint and organ damage. Canakinumab blocks its production to control inflammation, prevent joint and organ damage, and ease joint pain and stiffness.

Canakinumab is given as an injection under your child's skin. The dosage schedule for this medication may vary from once every two weeks to once every three months. Your nurse will give your child these shots at the doctor's office.

Canakinumab dosage is based on your child's body weight. Kids with systemic JIA who weigh 7.5 kg or more will receive 4 mg/kg once every four weeks, with a maximum dose of 300 mg.

Before your child starts treatment with canakinumab, your doctor will ask you about any history of infections your child has had in the past, or if there are any current signs of infection. As with other bDMARDs, canakinumab can make your child more susceptible to infections. Also, if possible, try to make sure your child gets any necessary live vaccines, such as chickenpox or measles, mumps, or rubella (MMR) before starting canakinumab.

Your child will have regular blood tests to watch for any rare side effects of canakinumab treatment, such as low levels of white blood cells.

We don't fully yet know how canakinumab could affect an unborn baby or a breastfeeding baby if the drug is passed through a mother's breast milk. So if your child is a teenager and sexually active, talk to her about the potential risks of an unplanned pregnancy while she takes this drug.

What Are the Possible Side Effects of Canakinumab (Ilaris®)?
Canakinumab's most commonly reported side effect is upper respiratory infection. Most of these infections are mild. Symptoms may seem like a cold, including runny nose or sore throat.

Other less common, but possible side effects are pneumonia, stomach pain, urinary tract infection, headaches, nausea, vomiting, and diarrhea. Some children may have an injection site reaction, or redness, swelling, or itchiness around the spot where the needle goes in.

Canakinumab could cause low levels of white blood cells. It may also raise the risk of infections. Serious allergic reactions are possible with canakinumab (as well as most other drugs), so watch for any signs, like rash, swelling of the lips or face, trouble breathing, or dizziness. Seek emergency care immediately if you notice these signs in your child.

How Can I Manage the Side Effects of Canakinumab (Ilaris®)?
Use the precautions listed on p. 29 to lower the risk of your child catching an infection.

ABATACEPT (ORENCIA®)

Abatacept is a biologic drug approved for use in children with JIA. It can lower disease activity and reduce

symptoms of JIA. Abatacept may be prescribed after another drug, such as methotrexate or leflunomide, has not worked well as an initial therapy. It may be used alone (monotherapy), or in combination with methotrexate.

What We Already Know

Abatacept is a biologic drug that blocks signals sent between T cells and other cells in your child's immune system. T cells are one kind of immune cell that are involved in the JIA disease process. By disrupting this communication between cells, abatacept can reduce or stop the increased inflammation associated with JIA.

Abatacept is given in prefilled syringes that are injected under the skin. These syringes are shipped to your home. The drug is also available as an infusion, which is an intravenous (IV) drip that's done at your doctor's office, a special infusion center or clinic, or in a hospital.

Dosage is based on your child's body weight. Infusions are about 30 minutes long and needed once a month. Subcutaneous injections (these come in prefilled syringes) are needed every week.

Children two years of age or older who take abatacept via injection will receive 50 mg if they weigh between 10 kg and 25 kg; they will get 87.5 mg if they weigh between 25 kg and 50 kg. Children six years of age or older receiving abatacept via infusion or intravenous drip will receive 500 mg if they weigh less than 60 kg; they will get 750 mg if they weigh between 60 kg and 100 kg . Children who have an active infection should not take abatacept. Like other biologics, it increases the risk of serious infections, so watch for the signs of infection in your child, and take precautions to prevent infection whenever you can.

What Are the Possible Side Effects of Abatacept (Orencia®)?

Side effects of abatacept may include cold, sore throat, headache, or nausea. Infusion-related reactions may occur with abatacept. These may happen during or shortly after the infusion. Signs include hives, trouble breathing, or

swollen face, eyelids, lips, or tongue. Other side effects of this drug in children may include diarrhea, fever, cough, and stomach pain.

TOCILIZUMAB (ACTEMRA®)

Tocilizumab is another biologic drug option for treatment of kids with JIA. Like canakinumab, it's a recombinant human monoclonal antibody. This means that a human antibody is genetically re-engineered to block production of another protein involved in systemic JIA: interleukin-6 (IL-6).

Tocilizumab is approved for use in kids age two or older who have either systemic JIA or polyarticular JIA. It can be used as monotherapy, or in combination with methotrexate or other cDMARDs. Tocilizumab can help lower your child's disease activity, thereby preventing joint and other organ damage and reducing your child's symptoms.

What We Already Know

Research shows that some kids with JIA make too much IL-6. Cells have "receptors" for IL-6 that tell them to ramp up their activity. These cells may then activate and do harm to healthy tissues. Tocilizumab can interrupt signals in this process.

Tocilizumab is given to your child either as injections you can administer at home or as an infusion. Dosage is also based on your child's body weight. For the intravenous option for polyarticular JIA, kids who weigh less than 30 kg receive 10 mg/kg every four weeks; kids who weigh 30 kg or more will receive 8 mg/kg every four weeks. For the intravenous option for systemic JIA, kids who weigh less than 30 kg will receive 12 mg/kg every two weeks; kids who weigh 30 kg or more will receive 8 mg/kg every two weeks. The subcutaneous dosage for polyarticular JIA for kids who weigh less than 30 kg is 162 mg every three weeks; kids who weigh 30 kg or more will receive 162 mg every two weeks. The subcutaneous dosage for systemic JIA for kids who weigh less than 30kg is 162 mg every two weeks or 10 days; kids who weigh 30 kg or more will receive 162 mg every week.

Children who have an active infection should not get a tocilizumab infusion. As with other biologics, it increases the risk of serious infections. It should be used with caution in anyone with a gastrointestinal perforation or active liver disease (this may be impossible to know, but it's listed on the drug's labeling), and is not advised for use by pregnant or breastfeeding women (which could include teenagers with JIA).

What Are the Possible Side Effects of Tocilizumab (Actemra®)?

The most common side effects of tocilizumab are upper respiratory tract infections, stuffy nose, headaches, high blood pressure, increased liver enzymes, and infusion site reactions. Infusion-related reactions could include: diarrhea, nausea, hives, breathing problems, stomach pain, chest pain, or elevated blood pressure. These may happen during or just after an infusion. So watch for any of these signs in your child if they occur after you've left the infusion center, doctor's office, or hospital.

Tocilizumab can increase your child's risk of getting an infection and lower his or her ability to resist infection. Rarely, tocilizumab could cause high blood pressure, or increased risk of abnormal liver function test results, infections, or malignancies.

How Can I Manage the Side Effects of Tocilizumab (Actemra®)?

To help prevent serious infusion-related reactions, your child may take a dose of acetaminophen (Children's Tylenol®) or diphenhydramine (Benadryl®) before his or her infusion appointment.

RITUXIMAB (RITUXAN®, MABTHERA®)

Rituximab is a biologic drug that targets immune cells called B cells. It seeks out and eliminates certain B cells involved in disease activity. By "turning off" these cells, rituximab may ease symptoms and reduce disease activity.

It's not FDA approved for use in JIA yet, but it may be prescribed off-label by some pediatric rheumatologists. Rituximab is prescribed after treatment with another biologic, such as a TNF inhibitor, has been tried but hasn't worked well enough for your child.

What We Already Know
Rituximab is a human monoclonal antibody. It's a protein made by living cells that is then infused into the body to seek out CD-20 B cells so they can be removed from circulation.

Rituximab is given as an infusion into your child's vein. It may be given as a high dose every two weeks for two doses, or as a lower dose once a week for four doses. Your child will go to a doctor's office, an infusion clinic or the hospital for these treatments. For infusions, your child will sit or lie down while a nurse inserts the needle and IV drip. Each infusion could take two to four hours.

What Are the Possible Side Effects of Rituximab (Rituxan®, MabThera®)?
Infusion site reactions are possible with rituximab treatment. These may occur during or shortly after infusions. Infusion site reactions could include: diarrhea, nausea, hives, breathing problems, stomach pain, chest pain, or elevated blood pressure. These may happen during or for up to a day after an infusion. So watch for any of these signs in your child if they occur up to one day after you've left the hospital or infusion center.

Rituximab could cause severe mouth, lip, or skin ulcers. It may cause painful skin reactions like blisters, peeling skin, rashes, or pustules. It can reactivate hepatitis B infection in anyone with an earlier infection. Rituximab may also raise the risk of infection with progressive multifocal leukoencephalopathy (a viral infection).

Rare but possible side effects of rituximab include nausea, abdominal pain, vomiting, diarrhea, achy muscles or joints, headaches, or dizziness. Children taking rituximab may have abnormal blood cell counts on their regular blood tests. They may have an increased risk of infection and some malignancies. While these side effects are rare, ask your pediatric rheumatologist to explain them, as well as any other concerns or questions.

How Can I Manage the Side Effects of Rituximab (Rituxan®, MabThera®)?
To help prevent serious infusion-related reactions, your child may take a dose of acetaminophen (Children's Tylenol® or generic brands) or diphenhydramine (Benadryl®) before his or her infusion appointment.

PART SIX

Beyond Drugs: What You and Your Child Can Do to Manage JIA

Your child's medications are the primary and most powerful weapons in the fight against JIA. Prescription treatments may work quickly — from days to weeks in many cases — to control inflammation and ease painful JIA symptoms. These medications have the most evidence and experience supporting their use and are the foundation in treating JIA.

Remember: JIA is a chronic illness. It doesn't magically go away just because your child's symptoms seem better. It has a natural history of ups and downs. Kids may relapse or "flare" at times. They may have bouts of pain, swelling, or stiffness that discourage them — and you. It is no one's fault, nor the fault of anything you may or may not have done.

Don't give up. You shouldn't assume that your child's treatments have necessarily failed, or that your child will not get better. Your health care team may be able to try another therapy if necessary, change the dose, or suggest other interventions that may be helpful. There is always something that can be done. For example, we've already mentioned **physical therapy (PT)** and **occupational therapy (OT)**. Your pediatric rheumatologist can prescribe these therapies and refer you to a PT or OT in your area. Therapists can work closely with your child to improve joint mobility, strength, and function. They can help your child learn to safely adapt their movements so they can do schoolwork, play games, or get involved in sports. Therapy can help them ease pain, stiffness, and other symptoms too.

What else can you do to help your child manage symptoms, ease fatigue and stress, reduce pain, and stay as healthy as possible? Fortunately, there are lots of things you can do — and they do not necessarily involve more medications. This is just a quick overview of these nondrug strategies for managing your child's JIA symptoms. Talk with your pediatric rheumatologist, nurses, therapists, and other health professionals to learn more and get specific guidance for your child's needs.

NUTRITION: EATING FOR HEALTH AND ENERGY

Food is your child's source of energy and sustenance. A healthy, nutritious diet of fresh, whole, natural foods can give your child all the energy necessary for busy days.

Yes, everyone enjoys junk food, fast food, or processed food now and then. You may feel overwhelmed with taking care of your child's health, your job, and family obligations, and if you have any time left, yourself. So it's hard to make freshly cooked meals all the time too. Here are some tips to keep in mind:

Eat a healthy breakfast every day. Just like Grandma used to say, a good breakfast provides energy for the whole day. If your child is slow to get up in the mornings due to joint pain or stiffness, serve breakfast after a warm shower or bath. Your kids and teens should not skip breakfast just because they're on the go unless it's absolutely necessary.

Eat more fresh veggies, fresh fruits, and whole grains. These foods have natural fiber, which aids digestion and regular bowel movements. They're better sources of vitamins, minerals and energy than processed treats like so-called nutrition bars. Bags of cut-up

carrots, apples, sugar snap peas, or melon can be good treats. Whole grains include whole wheat pasta, oats, and breads.

Drink water and other low-sugar fluids. Plain old water keeps your child hydrated without extra sugar or sodium. Offer low-fat milk. When you do serve juice, select kinds that are lower in sugar.

Enjoy variety. Children and teens may find the same meals boring, and cry out for fast or frozen foods instead. Mix it up when you can. If you normally buy apples, green beans, and oranges, look for kiwi fruit, honeydew melon, and red bell peppers once in a while. Produce in varied colors may provide more nutrients.

Disband the Clean Plate Club. If your child with JIA doesn't have the appetite to finish the whole meal, that's OK. Some JIA medicines can cause diarrhea, nausea, or stomach pain, so don't risk your child feeling worse by overstuffing their tummy. Other medications, particularly steroids, may cause increased appetite. In these cases, it's important to make sure your child is eating healthy food, and not overeating junk food. In most cases, kids will let you know when they are hungry or when they've had enough. (It's not necessarily your cooking.)

Sit down and eat together as a family. This can be hard for some families who are on different schedules, but mealtime is a great opportunity to relax, connect, and eat in a more leisurely way. Children with JIA may feel odd or lonely because they have to deal with medications, shots, or doctor's appointments. Mealtime is when they can just be part of the family and enjoy being with you.

If your child isn't able to get enough nutrition due to JIA symptoms or medication side effects, your doctor can refer you to a nutritionist, registered dietitian, or specialists who may be able to help. Don't be afraid to ask for help. Also, don't feel guilty if and when you can't do everything that people tell you to do, or if you can't afford to see a nutritionist or dietitian. Do what works for you and your family.

EXERCISE AND JIA: PROTECT JOINTS, STAY FIT, GET STRONG

You may think that kids with JIA shouldn't play sports or move around too much. They could injure their joints or make pain worse, right? Actually, activity is healthy for joints.

Kids and teens with arthritis need to stay active. In fact, regular exercise or physical activity helps your child improve joint range of motion or flexibility, build stronger muscles and joints, and improve stamina.

First, talk to your pediatric rheumatologist about the types of activity that are recommended for your child. You and your doctor will go over:

- Your child's current health status and readiness for physical activity
- Your child's exercise preferences, such as whether she likes to play soccer or he prefers swimming to team sports. The best physical activity is the one your child likes and will do regularly.
- Any joint protection tips or concerns your doctor has for your child
- What activities may be better choices for your child than others
- What signs of a sports-related injury or strain that you should watch for

Your child should get some physical activity every day if possible. And while we're on the topic... so should you! Exercise is great for everyone in the family. If your child's treatments are working, he or she can enjoy many team or individual sports, try dancing or swimming, help in the yard or garden, or play active games with friends, neighbors, and siblings. Bike rides, walks, fishing, or hitting golf balls with Grandpa: All of these are enjoyable activities for anyone with JIA. When your child's JIA is more active, it doesn't mean they should not do anything; it means they might need to change up their activities temporarily. If you don't move it, you lose it.

Regular physical activity for kids with JIA and everyone in your family should ideally include these three types of exercise (you don't have to do all three every day):

Range of motion exercises: These are stretches to improve joint flexibility and how far your child can move joints in different directions. A physical therapist is a great resource for simple stretches that kids of any age can do.

Strengthening exercises: These are moves that build stronger muscles through resistance or with small weights. These moves can be done every other day to rest muscles or if joints are sore.

Aerobic exercises: These include movements that pump up the heart and build up a sweat. This kind of exercise is done to improve cardiovascular health and stamina. Good aerobic workouts include walking, biking, swimming, dancing, raking leaves, or soccer. If your child is old enough to walk the dog, that's a good aerobic exercise too.

Other fun ways to get fit: If your child or teen with JIA is interested in trying other joint-friendly physical activities like yoga, tai chi, line dancing, or Zumba, why not join in and give it a whirl? You can enjoy a music-filled workout session together. Everyone in the family may benefit from regular exercise. It can also help burn off stress and anxiety.

The point is to do something (anything!) every day. Small amounts of frequent exercise are just as good as a long, formal workout. Find ways to incorporate physical activities into daily tasks (such as taking the stairs, parking farther away from the store, or raking leaves instead of using a leaf blower), as this is just as effective.

STRESS MANAGEMENT: PRACTICAL TIPS

Stress is a natural reaction to a JIA diagnosis or days when arthritis seems to take over your child's life (or yours). Kids with JIA may feel stress, anxiety, depression, or other mental health conditions — just like everyone else.

If you think your child needs professional treatment for a mental health condition, seek care as soon as possible. Psychologists, therapists, social workers, clergy, and other professionals can be very helpful in assisting your child and family in handling these issues. Speak with your child's health care professionals about a referral if you need one or don't know where to turn for help.

For managing everyday stress (whether it's related to JIA or not), these tips may be helpful for your child or teen:

Be open and honest. Talk with your child about what life can bring that may be stressful, regardless of the impact of JIA, as well as the additional issues raised by living with it. Be up front about the need to take medicine daily, or get regular injections or infusions. While you don't want to scare or discourage your child, it may be a good idea to explain what JIA is all about, and how it may affect his or her life.

Emphasize the positive. Focus your comments on what your child can do, not what's hard to do right now. Mention her artistic skills. Remind him that he's fun to be around. Make plans for family activities that are possible with arthritis, so everyone can have fun together. Point out that everyone has strengths, weaknesses, abilities, and disabilities. Everyone has to learn how to manage their lives as best they can.

Listen to your child's fears, questions, or concerns. It may be hard for children of any age to speak up about their worries. They may not know how to ask questions about things they don't understand. Sit down together in a quiet place and just listen. Let your child explain any fears about treatments, frustration with symptoms, or concerns about what may happen in the future. Every child needs the space to just talk it out. Rephrasing or reframing your child's concerns can often help them to better understand what's going on and help see ways through the difficulties.

Remind your child what he or she can do. Identify and help your child focus on the things that he or she can manage, like choosing outfits for school, which book you'll read together, picking the movie for the family to watch,

decorating the house for the holidays. Life is about management (even managing what feels like chaos), not control.

Walk through new experiences. If your child is about to begin infusions, talk about how that will go each step of the way. Children who are starting a new therapy program, sport, or school activity may want to walk through their plans with you too. Discuss how your child will walk into a new school and get to the right classroom. Do a little dress rehearsal for the school dance if your child is nervous about it. Practice, practice, practice.

Encourage independence and self-management. In time, kids with JIA grow up. They become adults. Some people with JIA may find that their disease goes into remission. For others, JIA sticks around. They have to live with a chronic illness. This includes learning to take care of their health and medical care. As your child starts to grow up, find ways that he or she can manage some things. It can start with doing their daily stretches on their own. They can be in charge of household chores like feeding the dog or putting plastic bags in the recycling bin. As children get older, they may be able to keep track of their meds and appointments without so much oversight from you. This can help them feel more independent, stronger, and self-driven. It can also free up your time and energy. Let your child grow and thrive as much as possible. Teach and allow experimentation and mistakes.

Guilt

Children might worry that maybe they got JIA because they did something wrong and parents might worry that their child got JIA because they did something wrong. This is not true. Children and families need to find ways to feel supported in their journey with a chronic disease. If you or your child feels guilt there are therapists and resources that can help.

OTHER WAYS TO EASE JOINT PAIN

While your child's medications can be effective at reducing inflammation, joint pain and muscle aches will still happen. Kids and teens with JIA may have flares, which are times when their inflammation surges. They can have painful, swollen, or stiff joints that are hard to move. They may struggle to button their pants or tie their shoes. And they may hurt for reasons other than their JIA. Remember that not all aches and pains are due to arthritis.

After extra physical activity like a soccer game or long day of holiday shopping at the mall, your child can also just feel achy and sore just like everyone else. Over-the-counter pain medications like ibuprofen or acetaminophen

can be helpful just as they are for everyone else, but here are some non-drug ways to ease minor or localized (in one joint) pain too:

Heat it up: Use a heating pad, warm and moist towel, or a hot shower to soothe and relax stiff, painful joints. Heat treatments are good in the morning for loosening joints to get ready for the school day. Putting rice in a sock or using a nonmetallic tie and heating it in the microwave, is an effective and inexpensive heating pad.

Cool it off: Ice is better for swollen, painful joints (inflammation). Use a bag of frozen peas, corn, or other small vegetables or a homemade ice pack wrapped in a cloth or towel, and apply it to the joint.

Wrap it up: Splints, braces, and wraps can help support weak or damaged joints by limiting their motion. Ask your physical therapist to fit your child for a brace or splint if needed. Extra support can be good for sports or other activities, or after a joint injury.

Rub it in: Try topical analgesics that you can buy at a local drugstore or grocery store or online. Don't mix these with heat or cold treatments. Use them on their own. They may provide some short-term relief, although not everyone finds them worthwhile.

Talk with your physical therapist or occupational therapist about additional ways to manage your child's muscle or joint pain. They can prescribe treatments, including splints and braces if needed, and suggest changes you can make to help your child adapt to different types of activity or movement. You may be able to make simple adjustments that make ordinary tasks easier for your child to do. Other options include TENS units, kinesio taping, and the use of mobility devices or adaptive equipment to minimize discomfort.

Pain around the joints doesn't necessarily mean that the pain is from the joints. Your child's pain could be caused by tendons, muscles, or ligaments too. You can treat this pain in similar ways as people without arthritis do: rest, cold and heat, or over-the-counter medications, such as topical agents.

TRANSITION: THE MOVE TO ADULT RHEUMATOLOGY CARE

As children with JIA get older and become young adults, they will gradually make a transition from pediatric care to adult care.

There is no set age when any child begins or ends this transition, but it typically begins in the mid-teens. Teenagers with JIA must learn to manage their own medications, go to medical appointments on their own, set and keep schedules for therapy or tests they need on a regular basis, and watch out for any problems that may require immediate medical attention. This requires practice. The more practice the better.

Your doctors and nurses can guide you and your teenager through transition. Some clinics or academic medical centers have detailed transition plans, which are guides or toolkits for transition to adult rheumatology.

So you're not doing this on your own.

Each person with JIA is different. Some may need more time to make this transition than others. As a parent, you may also be scared and unsure about "letting go" or allowing your child to be in charge of his or her own care. Here are some suggestions to keep in mind:

- Be patient and supportive during transition. It takes time for your child (and you) to feel confident about taking this step.
- Transition should occur when your child's disease is well controlled if possible.
- Let your child know how important it is to speak up at medical appointments, especially about any symptoms or possible medical side effects.
- As you have questions or concerns about your child's transition to adult rheumatology, ask your health care professionals, and other parents.
- When you and your child both feel comfortable with it, let your child attend medical appointments without you. Do this even if you aren't totally comfortable with it.
- Learn to hover less and less from farther and farther away.

As your child enters their teens, your physicians will begin to discuss the transition process with both of you. Ask questions, share your feelings or concerns, and work together to make a plan for this change in care. It's natural for both parents and children to feel nervous about becoming independent in/with regard to her arthritis management. Talk about it as a family and with your pediatric rheumatologist so everyone moves forward with confidence. ●

PART SEVEN

JIA at School: Coping Tips and Your Child's Rights

School is an essential part of every child's life. Living with JIA means that you and your child may have to make adjustments at times. Every child (with or without JIA) deserves a fulfilling and exceptional school experience at every age and grade level. You can partner with teachers, school administrators, school counselors, and school health professionals to ensure that your child's educational path is smooth and productive.

Kids with JIA want to be just like their friends. They'd much rather be in class or taking part in every school activity than staying home dealing with their arthritis or going to a doctor's appointment.

There are laws in the United States to protect the rights of children with JIA and other illnesses so they can have fair and equal access to an education. Here are some basic explanations of these laws and programs, but please do your own research to ensure that you are aware of all of your child's rights:

IDEA: INDIVIDUALS WITH DISABILITIES EDUCATION ACT OF 2004

Under federal law, children with chronic illnesses and/or disabilities may be allowed to apply for special educational services in all public schools if their illness results in a lack of appropriate educational progress. This law, the Individuals With Disabilities Education Act (IDEA), was reauthorized most recently in 2004, and is administered through the U.S. Department of Education. Even babies and toddlers up to age two can access early educational intervention services so these young children can learn and develop as they prepare for their future years in school. It can also apply to students through their 22nd birthday.

IDEA's purpose is "to ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special educational and related services designed to meet their unique needs and prepare them for further education, employment and independent living." This program only applies if their educational progress is not sufficient. It's likely that you will need to apply for accommodations in writing, and you will need to follow the required legal process. For more information, check these helpful resources:

The Individuals with Disabilities Education Act (IDEA) website: sites.ed.gov/idea

The Center for Parent Information and Resources: www.parentcenterhub.org/iep

The National Center for Learning Disabilities: www.ncld.org/archives/reports-and-studies/idea-parent-guide-2

INDIVIDUALIZED EDUCATION PROGRAMS (IEPS)

What does this mean for your child? Every child with JIA is unique, and every community's public school is different too. But these services often include the development of an IEP:

Teachers and administrators may be able to work with you to develop an Individualized Education Program (IEP) for your child. This detailed plan will offer goals for your child's education and a framework to achieve them.

This can include special services or accommodations. The IEP is designed to fit your child's unique needs and strengths, and to help your child succeed in the general education program as much as possible. Your child's IEP can also provide steps to help your child access after-school activities, school sports, and other programs at your local school.

Other services some children may be able to access through IDEA include:

- Speech therapy to help with any language delays or challenges
- Occupational therapy to help your child adapt movements or activities so they're easier to do with arthritis
- Physical therapy to help your child manage pain, mobility issues, or dexterity problems that interfere with schoolwork
- Counseling services to address any mental health issues, behavioral challenges, or improving social skills
- School nurse services
- Social worker services for your child and your family
- Adaptive equipment, including technological devices such as tablets, voice recognition software, etc.

504 PLANS

Your child may also qualify for what's called a 504 Plan. This is a detailed plan for supports, modifications, services, accommodations, or equipment that your child may need for his or her education to ensure equal access to the curriculum. It is a civil rights legislation. Unlike an IEP, educational progress is irrelevant to one's eligibility for a 504 plan.

504 plans may include anything from visual aid tools, special computer keyboards, special seating in the classroom to accommodate your child's mobility issues, special arrangements for taking tests if necessary, help from the school nurse to administer medications or address any medical emergencies that occur at school, and therapy and counseling. 504 plans are designed to modify the school environment and services to support and accommodate your child so he or she has the same access to the educational curriculum as his or her peers do. That's different from an IEP, which may require access to special educational services for your child. It just depends on your child's particular needs.

This website has more information about your child's rights to equal access to education, important resources, educational services or accommodations that schools must provide, and tips for parents: www.wrightslaw.com. You may also go to your state's Department of Education's website to find more state-specific information or services for your child.

In addition, the Federal Department of Education has created another online resource just for parents and caregivers of kids with chronic illnesses and disabilities called the Early Childhood Technical Assistance Center. Its website has even more information in both English and Spanish on:

- Your child's rights to public education services and access under the law
- Simple explanations of various parts of the IDEA law that are important for your family
- Contact information for services in your state
- Information that may enrich your role in your child's educational development, including an early childhood online bookstore

Check out the Early Childhood Technical Assistance Center website at: ectacenter.org/families.asp for more information.

An additional resource provided by the Arthritis Foundation has a great overview of educational rights: www.kidsgetarthritistoo.org/resources/educational-rights-kit

HELPFUL TIPS

You can take a few proactive steps to help your child stay on track during the school year. You can also work with teachers, administrators, and counselors to address any specific needs your child may have. Just like you, they want your child's educational experience to be successful. Work together, ask your pediatric rheumatologist's office staff for advice when you need it, and make sure you know your child's rights.

Before the school year begins — especially if your child is about to enter school for the first time or is starting at a new school — reach out to the school administrators. Set up an appointment to talk with the appropriate staff about your child. Explain what JIA is and how it may affect your child at times. Let them know that JIA's symptoms may not always be visible, but their impact on your child's mobility or well-being may be severe at times.

Ask your child's school for a child study evaluation — or the equivalent term in your state — to start the process for qualifying your child under Section 504 or IDEA as the first step. All of these supports and accommodations may then be provided within those constructs. Remember: Your child has legal rights to a free and appropriate education. This does not depend on your school or teachers being "nice" or accommodating. Stick up for your rights.

Let them know that your child may need to have regular medical appointments, infusions at the local hospital or clinic, and possibly, days out of school due to illness. Discuss the fact that your child may need to take medications during the school day, and how the school nurse or other health staff may be needed to assist. Discuss the potential increased risk your child may be at for infectious diseases due to his or her disease and its treatment. Together, you can develop a plan to minimize exposures to other ill children and discuss ways you will be notified if such an exposure occurs.

If you're unsure about how JIA may affect your child's schoolwork or participation in school activities, ask your pediatric rheumatologist to talk with you at your child's regular appointment. Talk about your child's individual health and specific challenges. Find out what type of schedule changes or accommodations your doctor may suggest for your child. Have your physicians write supporting letters with their recommendations to the school to facilitate the implementation of these supports and accommodations. Remember, every child is unique.

JIA symptoms may not affect your child's school experience at all. If that is the case, it's great. However, this is just like doing fire drills. You hope there will never be a fire, but if there is one, everybody should know what to do. The same is true with how JIA impacts your child's school experience. Be aware of how JIA could make some tasks more difficult at times, so you can work with your child's teachers to request adjustments if your child needs them. Don't expect problems to occur — just be aware of challenges that may be possible so you can address them.

Here are some ways that JIA could affect certain classroom tasks or just a normal day at school:

Stiff or painful fingers or hands could make gripping a computer mouse, typing on a keyboard or tablet screen, or holding a pen or pencil more difficult. If your child's grip strength is weak, doing art projects or sports that require gripping equipment could be challenging. Writing by hand for a long time, such as writing an essay or taking a test in class, could also be hard for your child to do at times. They also may need extra time to complete written assignments in class and examinations.

Morning stiffness is common with JIA. So your child may need to have adjusted schedules in some cases. Some

activities may be harder for your child in the early morning hours at school.

JIA can cause mobility challenges for some kids. Your child may need more time to get from class to class, or to complete certain physical tests or activities. Your child's teacher may be able to rearrange seating in the classroom so your child can move easily from activity to activity. Plans should also be made to ensure your child can exit the building rapidly during an emergency.

Some kids with JIA can have fatigue. That's not just feeling sluggish in the afternoons. Fatigue can be severe. Your child may need to take breaks or be careful about overdoing some activities.

Stiffness and pain in the hips, knees, back, or neck joints, and feet may spike after sitting for too long at a desk or table. Let your child's teachers know that he or she may need to get up and stretch often, walk around the classroom, or even work at a standing desk at times.

Adjustments for physical education. Your child may need to have their physical educational experiences adjusted depending upon how JIA affects them. They may also find it difficult or embarrassing to change into gym uniforms, or prefer to wear long pants and long sleeves rather than put on sunscreen for PE.

Transportation and emergency planning may be necessary.

QUICK, EASY ADJUSTMENTS

Think about all the activities your child may want to participate in during the school year or summertime, not just classes. Think about support and accommodations that your school can make. For example, if your child takes a medication that causes extra sun sensitivity, teachers and coaches may need to know that your child needs to wear protective clothing and sunscreen when engaging in outdoor sports or activities. That's not a big deal, so don't feel like you are being demanding. Besides, it is medically necessary, not optional.

Children with JIA want to enjoy all the school activities that they can and participate with their friends, just like everyone else. They don't want to hang back, sit on the sidelines, and watch everyone else. With successful management of their JIA, they don't have to. They can do it all: classwork, school plays, sports, arts and crafts, band, service projects, you name it. There may be times or situations when they have to make adjustments to how they participate in a school activity, but that does not mean they must miss out on participation.

There are laws in place to ensure that your child has equal access to public school education. If your child attends a private school, you may not be able to access the services required by federal law, so talk with your child's school administrators about any accommodations they do provide. While private schools are not necessarily legally required to provide as much as public schools — unless they accept federal funds — many want to ensure a fully inclusive environment for all their students and could even do more for your child than a public school.

Should your child attend public school over a private school or parochial school? That question can be answered only by you. Choosing a school that's right for your child is a very personal decision. You may choose to enroll your child at a private or parochial school over the local public school for various reasons, including educational mission or style, religious identification, or other important factors. Here, we will go over some of the services and accommodations that are required by law in public schools:

MEDICAL APPOINTMENTS

Living with JIA means regular doctor's appointments for checkups and tests. Your child may also need to take time off from the school day for unexpected medical appointments when they are experiencing symptoms that just don't

seem normal, like a sudden rash or vision problem. If your child takes a biologic drug that's infused, regular visits to the infusion clinic may mean time out of class.

It's a good idea to prepare for the school year by making everyone aware of your child's arthritis and any potential needs. Before the school year begins, communicate with your child's school administrators and teachers about expected, regular medical appointments for checkups, injections or infusions, or tests.

FLARES HAPPEN

At times, your child or teen may experience a JIA flare. That's a period of time when inflammation flares up and disease is active. Flares can happen with little or no warning. They can occur even if your child's treatments seem to be working well.

Flares could happen at any time. Your child may need to be absent from school for a short time. In these cases, work with your child's teachers to ensure that any schoolwork that can be done at home is sent to you promptly. Make sure that all teachers know that your child needs to be out of school to attend medical appointments or rest at home. Have a plan in place to help your child keep up with assignments while he or she is out of class.

Work with your child's teachers to make sure that any quizzes, tests, or exams are either conducted when your child can return to class, or done at home, if possible. Your child may also need extra time for tests or homework and should receive these accommodations, whether due to a flare or not.

INFECTION RISKS

While all kids are at risk of getting an infection, your child may be at higher risk due to his or her medications for JIA. Your child's pediatrician and pediatric rheumatologist will go over how and when to set up the vaccinations your child needs.

In addition to vaccinations, these tips may prevent picking up infections at school:

- Make sure your child knows to **wash their hands often**, such as after a trip to the bathroom, playground, gym, or cafeteria.
- Teach your child **the signs of a friend or classmate who's getting sick**: sneezes, coughs, flushed face, feeling hot all of a sudden, runny nose. Let them know it's smart for them to stay away from anyone who seems sick, and to let the teacher know right away.
- Dress your child in **warm, protective clothing in winter**, like gloves and hats, and rainproof jackets or boots.
- Stay aware of **emails, texts, or notices from your child's school** about outbreaks of flu or other infectious diseases.

TAKE PRECAUTIONS AND PLAN AHEAD

You already know how important it is to plan ahead when you're a parent. You can't prepare for everything... nobody can. But there are a few simple things you can do to help your child be as healthy, happy, and successful as possible:

Stick to your treatment plan. Make sure your child takes prescribed medications on schedule. Keep up with regular doctor's appointments and tests. Follow your doctor's suggestions and recommendations.

Encourage your child to exercise and eat nutritious foods. It's easy for any kid with JIA to get discouraged and

think they can't do what other kids do. Let them know that they can. Get the whole family involved in physical activities. Go for a walk with the family dog. Enjoy a stroll through the park in springtime. Take a swimming class. Sign up for basketball at the local community center. Make an effort to eat whole, fresh foods instead of junk food or fast food whenever you can.

Strike a balance. Keep track of all of your child's activities, including school and homework. Make sure that your child isn't trying to do too much. This can easily lead to burnout, or even lead to muscle and joint pain from overuse. Rest is important too. Kids with JIA need to enjoy an active lifestyle, but they also need to just chill sometimes. So do you.

Manage stress and anxiety. We all feel overwhelmed at times. Children with JIA may feel stressed when their disease is flaring, when their illness makes enjoying activities with their friends too hard to manage, or when a peer says or does something negative toward them. They can resent having arthritis — and that's quite natural. Children with JIA often say that they hate arthritis. It's natural for kids and teens to want to feel "normal" or "just like everyone else." Feeling different is stressful. Having a chronic illness can even lead to depression or anxiety. If you notice any behavioral or mood changes in your child, get help right away. Let your child's health care team and school know that you're concerned about your child's stress levels. Ask them to let you know if they are noticing changes that could indicate behavioral or mood issues. Your child may need counseling or therapy, as well as changes to his or her schedule or routine.

Create good sleep habits. If your child gets a good night's rest, he or she can feel recharged the next day. Lack of sleep or poor sleep has the opposite effect. Active kids need to get enough rest. Make sure your child's bedroom is as cool, dark, and quiet as possible during sleep hours. Set a schedule: Bedtime should be the same time every night if possible. Lights, tablets, phones, TVs, and video games should be shut off at that time. Take a bathroom run before lights off. This may help reduce the need for your child to get up and stumble through a dark bedroom in the middle of the night.

Plan ahead for school outings, day trips, or overnights. Your child may want to take part in activities that take place far outside of school, including everything from field trips to camping sleepovers in the great outdoors. There's no reason your child has to miss out. Plan ahead with the organizers if your child needs to have an injection or take any oral medications with food, or if your child needs help with any particular physical activities, like hiking or watersports. Be flexible! ●

PART EIGHT

Medication Costs: How to Get Help

It's very important for your child to stick to his or her treatment plan and take prescription medications on schedule. These drugs can be very expensive. Medical bills, including costs for prescription drugs, can be a huge burden for many families. If you're worried about being able to afford your child's prescriptions, there may be some ways for you to get some help.

Patient assistance programs: Many drug manufacturers take part in Patient Assistance Programs and other discount programs for JIA medications. These programs can be anything from a discount on your out-of-pocket cost to a coupon for the drug redeemable through certain retailers. Check out this website from the Partnership for Prescription Assistance, a nonprofit organization that provides a clearinghouse for patient assistance programs for families like yours: www.pparx.org/prescription_assistance_programs/list_of_participating_programs

Manufacturer's websites: You can also look up the website for your child's individual prescription medications. Just use any search engine (like Google or Bing) to find the drug's public website. You will see links to programs to help you lower your costs to fill these prescriptions. Each one works differently, and your insurance policy will determine whether you are eligible for these discounts. But it's worth checking out. You may be able to access deep discounts for your child's drugs, or in some cases, not have to pay anything out of pocket.

Note: Insurers and pharmacy benefits managers (PBMs) may not pass manufacturer's discounts, rebates, or coupons on to you, the consumer. This is currently a hotly debated topic in our country and an ongoing issue. Contact your representatives in your state legislature and in Congress to make your voice heard on this issue. Arthritis advocacy organizations are also fighting for patients' rights, more transparency in drug pricing, and more affordable medications for everyone.

Drug discounter sites: There are several independent companies that locate discounted prices for almost any prescription drug. You simply go online, sign up for these programs, and then search for your child's prescription medication on their site. These sites search instantly for various prices at pharmacies (including online pharmacies) so you can find the best price. They also provide coupons for discounts that can be texted or emailed to you. It may not lead to a sizable discount on every drug, but prices can vary a lot from different pharmacies or retailers. These sites include goodrx, Blink Health, OneRx, WellRX and others. Some of these discount programs send you a card that you can use at participating pharmacies to get discounted prices when you pick up your prescription. **If your insurer or PBM requires you to use a certain pharmacy (or mail-order pharmacy), these may not apply to you.**

Your doctor: If you cannot afford your child's prescription medications, let your pediatric rheumatologist know right away. You do not want to skip any doses or leave prescriptions unfilled under any circumstances. Your pediatric rheumatologist and office staff may be able to help you find discounts, coupons, and assistance programs so these drugs are affordable. They may be able to intervene with your insurance company if you're having trouble getting them to cover a new drug. They may also be able to prescribe other options if one drug is just too expensive for you to be able to afford.

Your employer's benefits manager: If you get your insurance through your job or your partner's job, and you have any issues with drug coverage from your insurer, talk with your benefits manager at work. These professionals are experts at navigating your particular policy or coverage. They often work with insurance agents

or the insurance companies directly, and may be able to explain your options or tell you how to make an appeal for coverage.

Your state insurance commissioner and other elected officials: Each state has its own insurance commissioner. Go online to find the one in your state, and check out their website for news about insurance issues in your area. Find out how you can file a complaint or whom to contact to get help. You can also call your state representative or member of Congress to urge them to support specific legislation or just to be aware of issues facing families like yours.

If you feel that your prescription drug costs are burdensome, you're not alone. Trying to deal with medication costs and insurance policies can be incredibly stressful. It will make you angry at times and leave you feeling confused. Remember: Help is out there. There are many people and organizations that want to connect you to helpful resources. You can also reach out to other families with kids who have JIA. Connect with them via social media, online support groups, or parent meet-ups in your community. They may have great ideas for you to find lower prices or access programs that provide deep discounts for your child's medications.

PART NINE

Living With JIA: The Future Is Bright

This is a time of optimism for kids and teens living with JIA, as well as for you as a parent. Decades of research have led to disease-altering, life-changing therapies for these diseases. In most cases, kids with JIA can now stop arthritis before permanent joint damage can occur. They do not have to face the level of disability that this diagnosis once meant. Kids with JIA no longer need joint replacement surgeries as often or as early as in the past. These incredible changes are the result of successful research and development.

What's in the future? Current research on the role of environment and genetics in JIA may one day lead to even earlier diagnosis. More effective and personalized therapies with fewer side effects may make JIA even easier to manage. One day, we will have a cure for JIA.

Be hopeful and optimistic. Your child will be able to lead a full, long, and enjoyable life with JIA. Children and teens with JIA grow up and live full, active lives, experiencing college, careers, travel, and having their own families. They don't feel that JIA holds them back or limits what they can do — because they are doing it all! They can follow their dreams and achieve every goal imaginable — everything they want to do, and in their own way.

You and your child have a very exciting and fulfilling future ahead of you. You have a great support network, helpful resources, and partners to help you conquer any challenges that JIA may bring. ●

About the Editors

HARRY L. GEWANTER, MD, FAAP, MACR

Dr. Gewanter was born and raised in Brooklyn, New York. He attended Duke University for his undergraduate studies and then went on to Wayne State University for his medical training. After graduation, Dr. Gewanter attended the University of Rochester/Strong Memorial Hospital for his pediatric internship and residency. He then performed a fellowship in pediatric rheumatology and general academic pediatrics and practiced for two years in Rochester, New York before moving to Richmond, Virginia. He has since worked within pediatric practices and at Children's Hospital of Richmond. Dr. Gewanter was the first Walter Bundy, Jr. Professor of Community Pediatrics at VCU from 1999 to 2001. He was also the first pediatric rheumatologist to receive the American College of Rheumatology's Paulding Phelps award in 2013. Beyond pediatric rheumatology, Dr. Gewanter has special interests in all issues relating to Children and Youth with Special Health Care Needs (CYSHCN), especially the difficulties associated with special education, as well as advocating on behalf of all children and people with disabilities. He is known for his untiring advocacy activities at the local, state, and national level.

THOMAS J. A. LEHMAN, MD

After graduating Phi Beta Kappa from the University of California at Berkeley, Dr. Lehman graduated cum laude from Jefferson Medical College in Philadelphia. He trained in pediatrics and pediatric rheumatology at Children's Hospital of Los Angeles followed by two years in the U.S. Navy and then another two years of research training at the National Institutes of Health in Bethesda. He then returned to the faculty at the University of Southern California and the clinical faculty of Children's Hospital of Los Angeles. In 1987 he was recruited to lead development of a pediatric rheumatology program at the Cornell University School of Medicine and the Hospital for Special Surgery in New York City. After 30 years he has retired as a senior scientist and senior physician at the Hospital for Special Surgery and professor of clinical pediatrics at the Weill Medical College of Cornell University.

HEATHER TARANTINO

Heather is the mother of a child living with JIA. She lives with her two beautiful daughters and husband. They love to play board games, go for walks in the park, and play outside together. Professionally Heather has been a nurse for 17 years, currently working as a family nurse practitioner. She was motivated to review this document because it is important for her to be involved in a project that empowers parents and gives them the tools and resources they need to take care of their children with JIA as best they can. As a mother and a nurse she knows that feeling supported, particularly when it comes to chronic disease, is essential to the healing process. She found this document to be a valuable and essential resource for parents.

A special thank you to our partners at Bristol-Myers Squibb for their generous sponsorship of this important patient resource.

Glossary

Analgesic
Drug that treats pain only, not inflammation. Oral analgesics are drugs like acetaminophen that are taken by mouth. Topical analgesics are skin rubs or creams that are used to ease minor, localized joint pain.

Anxiety
A general uncomfortable feeling of nervousness and apprehension about something that is happening or about to happen.

Approved
The Food Drug Administration (FDA) has issued permission for a given medication to be commercialized for a specific disease entity.

Assistive devices
Tools or adaptive products that allow a person with a disability or impaired dexterity to perform tasks with more effectiveness or ease. Assistive devices include grips that fit around pencils or pens, long-handled reachers that allow a person to grasp items more easily, or swivel seats for a chair or car seat.

Autoimmunity
State in which your own immune system becomes dysfunctional and starts attacking yourself. Examples of autoimmune diseases include juvenile idiopathic arthritis, rheumatoid arthritis, and lupus.

Auto-injectable devices
Devices prefilled with medication that a parent or adolescent patient can administer by injection on their own at home. Auto-injectable devices may look like pens. They are designed for quick, easy use.

B cells
A type of white blood cell or lymphocyte that secretes antibodies and plays a prominent role in the adaptive immune system. B cells may be involved in the pathogenesis, or the development, of JIA.

Biologic
A term for highly sophisticated, genetically engineered medications that target specific components that cause inflammation. These medications are made from living or "biologic" material, and are widely used in rheumatology and oncology.

Biosimilar
Genetically engineered medication designed to have structure and activity highly similar to the original biologic licensed, which is called its "reference" product.

Clinical trial
Lengthy, costly process that new medications must go through in order to be approved by the FDA. Usually the new medication is compared to the current standard of care (best treatment available) or to placebo (no treatment).

Combination therapy
Treatment that involves being on more than one medication in order to control the disease. Some medications may work better when used at the same time (i.e., methotrexate and a biologic).

Comorbidity
Refers to a second or additional disease someone might have aside from his or her primary condition. Children with JIA may also have uveitis, for example.

Complete blood count (CBC)
This is a blood test that measures a person's white cells (army against infection), red cells (cells that carry oxygen to tissues), and platelets (fragments of cells that prevent us from bleeding).

Contraindications
Statement in a drug's prescription insert or label that's used often to notify the user about situations when a drug or procedure could cause possible harm (i.e., methotrexate is contraindicated during pregnancy due to the high risk of birth defects).

Copayments
Portion of the cost of medication, procedure, or hospital stay that a patient is responsible for paying. Insurance companies may pay most of the cost of a treatment, but a person's copayment or "copay" is what they must cover "out of pocket."

Corticosteroids
Highly effective medications used to treat inflammation. They have multiple possible side effects, so patients should not be on corticosteroids for a long period of time. Also called glucocorticoids.

Depression
A potentially serious medical condition in which a person has a persistent feeling of sadness, hopelessness, and difficulty finding pleasure in things that have normally provided them pleasure. Depression may occur in people with chronic diseases like JIA, and it should be diagnosed and treated by a mental health professional.

Disease activity
Objective measurement of inflammation attributable to the disease. Doctors have developed tools and scoring systems to assess how mild, moderate, or severe a person's disease state is at a given point.

Disease-specific markers
Blood test results that are associated with a given disease.

DMARD
Stands for disease modifying anti-rheumatic drug. Sometimes, these drugs are called "conventional DMARDs." These are medications that may not only alleviate symptoms but slow or stop the progression of the disease (i.e. preventing joint erosions).

Dosage
The amount of a given medication a patient takes. Dosage can be expressed in milligrams, micrograms or other measurements.

Erosions
Breaks in the surface of bones in the centers of joints that may be seen on X-rays. Synovitis (the inflammation of the tissue lining the joints) is the main trigger of joint erosions. Erosions are the result of too much bone resorption (the destruction or loss of bone), and not enough bone reformation (the generation of new bone).

Evidence
Evidence is the presence of information through research studies regarding a given intervention, such as a course of medication, surgery, or physical therapy. The evidence can be positive or negative. Many physicians and nurse practitioners will use the scientific evidence to make their treatment choices for a particular patient.

Fail First
Terminology used by providers to describe step therapy, as patients must first fail on less expensive medications before an insurance company will cover the cost of potentially more effective, but costly options.

Flare
An episode of worsened disease activity in JIA. Also called a "flare-up." During a flare, arthritis symptoms like pain, stiffness, fever, or fatigue may be worse and even debilitating.

Generic drug
Medication that is equivalent to the branded (original) drug in dosage, quality, and route of administration. Usually generic drugs are less expensive versions of the same drug, but the difference in cost varies from product to product. Over-the-counter generic drugs often are called "store brands."

Glucocorticoids
Another term for corticosteroids. Highly effective medications to treat inflammation. They have multiple possible side effects, so patients should not take them for a long period of time.

Guidelines
In JIA, treatment guidelines are a set of detailed recommendations for the treatment of patients at certain stages of their disease or when therapies do not work sufficiently. Guidelines are recommendations designed for use by health care professionals to help guide them in prescribing treatment. Guidelines are created by a panel of experts in the disease, including physicians and, in many cases, patients and/or their parents.

Idiopathic
No known cause. Term used to describe diseases for which the cause or exact origin is not known at this time.

Inflammation
Process where your white blood cells (army against infections) and their products become hyperactive. Physical signs of inflammation include redness, warmth, swelling, and pain, such as at a joint.

Inflammatory markers
Blood tests measure these markers to determine how inflamed the body is at a given point. These markers are routinely measured in rheumatology.

Infusion
A term used to describe a drug that is slowly dripped into a patient's vein by a health care professional, usually at a hospital or infusion clinic.

Interchangeable
Designation given to a biosimilar beyond its structural similarity to the original drug, after it has proven clinical efficacy in a patient. The practical implication is that an interchangeable biosimilar may be substituted for the reference product without intervention of a physician.

Interleukins
Glycoproteins that are released by white blood cells and which regulate immune system responses. There are different types of interleukins that are numbered. IL-1, IL-1-beta and IL-6, for example, may play prominent roles in JIA. Certain biologic drugs may "inhibit" or block a particular interleukin, such as an "IL-1 inhibitor."

Intra-articular
Term used to describe a treatment injected into a joint.

Intramuscular
Term used to describe a treatment injected into a muscle.

Intravenous
Also called "IV," a term used to describe a treatment infused into a vein so it enters the patient's bloodstream.

Monitoring
Monitoring relates to the need of frequent, objective assessments (like blood tests) to measure how a patient's disease is progressing (or not) or to watch for side effects from medications.

Monotherapy
When only one medication is taken for disease treatment.

Nonsteroidal anti-inflammatory drug (NSAID)
Drug used to treat inflammation that may be the underlying cause of joint pain and swelling. Common NSAIDs include aspirin, ibuprofen, naproxen, and ketoprofen. Usually used short term in JIA.

Occupational therapist
Also called an "OT," licensed health care professionals who specialize in therapy to restore mobility, independence, and the ability to perform occupational tasks at work or school. Occupational therapists may help a patient adapt movements for less pain or improved dexterity, or train a patient to use assistive devices.

On the market
Medications that are currently approved by the FDA, commercialized, and available for patients to use or for health care providers to prescribe.

Pediatric rheumatologist
Physician who specializes in systemic autoimmune illnesses and arthritis in children and adolescents. Training comprises three years of internal medicine and later a three-year fellowship in pediatric rheumatology. When JIA patients become adults, they will make a gradual transition from treatment by a pediatric rheumatologist to a rheumatologist, although this occurs at different ages depending on the individual person.

Physiatrist
An internist with additional training in physical medicine and rehabilitation medicine, also called "physiatry." A physiatrist may oversee a team of health care professionals in the treatment and rehabilitation of a patient who has impaired mobility due to illness or injury.

Physical therapist
Also called a "PT," licensed health care professionals who specialize in therapies that reduce pain and improve mobility in patients of all ages. Physical therapy usually does not involve drugs or surgery. Physical therapists may guide patients in certain exercises, rehabilitation treatments, or heat or cold therapies to ease pain, for example.

Prior Authorization
A process through which a provider must request authorization from the patient's insurance company to prescribe a particular treatment. The process is often lengthy and complicated, and can delay important patient care.

Recommendations
Statements made by a committee comprised of very knowledgeable experts on the specific disease. They help health care providers follow a basic algorithm but in the end, treatment decisions should be made on an individual basis.

Reference drug
Relates to the original pioneer drug that a biosimilar or interchangeable drug is designed to copy. The biosimilar's reference drug is the original biologic drug.

Remission
State in which signs and symptoms are controlled, and based on objective examination by the doctor, the disease activity is low. This is the ultimate goal in treating JIA.

Rheumatologist
Physician who specializes in systemic autoimmune illnesses and arthritis in adults. Training comprises three years of internal medicine and later a two- to three-year fellowship in rheumatology. When JIA patients become adults, they will make a gradual transition from treatment by a pediatric rheumatologist to a rheumatologist, although this occurs at different ages depending on the individual person.

Self-administration
Term used to characterize a medication that may be administered by the patient without a health care provider being involved. Examples include subcutaneous prefilled syringes or subcutaneous auto-injector devices ("pens").

Side effects
Unwanted or undesirable effects of certain medications or procedures. All medications have side effects and should be monitored carefully.

Specialty pharmacy
Specific segment of a pharmacy or hospital that deals with high-cost and complex medications. A specialty pharmacy may fulfill a prescription for a biologic DMARD, for example. Specialty pharmacies may be divisions of large chain pharmacies, but supply the medications via mail or home delivery service.

Step therapy
The process in which an insurer requires providers to follow "tiers" based on cost when prescribing medications. In most cases, the least expensive medication must be prescribed first, and progression to other options is allowed only after a patient has been shown to "fail" on the initial medication.

Synovium
Membrane that surrounds the joint and produces synovial fluid, which "lubricates the joint" for smoother movement.

T cells
A type of white blood cell that's part of your immune system. T cells are normally activated when they find a sign of a foreign invader. When this happens, they send signals to wake up other parts of your immune system to deal with the foreign invaders like bacteria or viruses.

TNF
Tumor necrosis factor (TNF), a protein which may play a major role in the inflammation seen in JIA.

Topical agents
Skin creams, rubs, or gels that are used for localized, minor joint, or muscle pain. Topical agents may contain different active ingredients. They are not used for widespread or persistent pain.

Transition
The period of gradual shifting from treatment by a pediatric rheumatologist to a rheumatologist, or from treatment in a pediatric clinic or office setting to one that serves adults with rheumatic diseases. Transition usually occurs over a several-year period in a patient's mid to late teens. Some hospital networks have formal transition programs for people with JIA that include steps to follow and support from a social worker, for example.

Treatment plan
A comprehensive plan for the treatment and ongoing management of disease. A treatment plan is the result of a conversation between the patient's parent(s) (or, in the case of a teenager with JIA, the patient) and physician or other health care providers. It outlines a strategy on how to cope with the disease. Treatment plans may include medications, physical therapy, exercises, and diet, for example.

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