



You,
Your Child

&

Arthritis



The Arthritis
Society

A message from our Sponsor

The future matters to our communities. Making contributions that have a lasting, positive impact is the driving force behind TD Bank Financial Group's many community giving programs.

TD Bank Financial Group is pleased to provide financial support to The Arthritis Society for the production of *You, Your Child and Arthritis*.

Finding useful information about children's health issues can often be difficult for families. As the sponsor of this new edition of *You, Your Child and Arthritis*, it was our goal to help provide families coping with arthritis, access to current and reliable health information. Working together with the Arthritis Society, TD hopes to ensure a brighter future for all Canadian children.



Introduction

The mission of The Arthritis Society is to search for the underlying causes, and subsequent cures for arthritis, and to promote the best possible care and treatment for people with arthritis. The Arthritis Society provides education, support and solutions to people living with arthritis, giving hope for a better life – today and tomorrow.

The Arthritis Society is pleased to present the fourth edition of *You, Your Child, and Arthritis*. This publication provides factual information, and should serve as a basis for you to ask questions and gain further knowledge about juvenile idiopathic arthritis and how it may affect you and your family.

4th Edition
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(June 2005)

You, Your Child and Arthritis was originally produced by the late Dr. Abraham Shore and Dr. James E. Boone. The 3rd Edition was revised by Dr. Ronald Laxer.

We also thank Dr. Alex Levin and Dr. Nasrin Tehrani for their contributions to the section on eye problems and eye care.

Foreword



In 2004, a book entitled *I am Brave: Children Living with Arthritis* was developed to give hope and inspiration to children living with arthritis. During its development, children from across Canada were asked to draw pictures and write stories about the emotional and physical impact of the disease on their day-to-day life.

The fourth edition of *You, Your Child & Arthritis* presented an opportunity to republish the compelling and creative artwork first showcased in *I am Brave*. The end result is a fun and informative book for children living with arthritis and those who care about them. On behalf of The Arthritis Society, I would like to thank the many artists who made such a meaningful contribution to this book.

John E. Fleming
President & CEO, The Arthritis Society

Artists

Bailey - page 10

Brandon - page 15

Callah - page 33

Chesney - page 20, 21

Ericka - page 17, 19, 20, 23

Jaelyn - page 12

Jennifer - page 27

Laurence - page 10, 28

Madeleine - page 14, 19, 31

Melanie - page 11, 32

Rebecca - page 18

Tricia - page 15

You, Your Child and Arthritis is a valuable resource for children and families with newly diagnosed juvenile idiopathic arthritis (JIA) as well as a useful reference for those who have had arthritis for years.

This edition describes the newer terms which are now frequently used to classify the types of chronic arthritis in children and provides updated information on medications including the currently available biologic agents.

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President, Canadian Pediatric Rheumatology Association

You, Your Child and Arthritis was created by The Arthritis Society in conjunction with leading experts in pediatric rheumatology, young adults with JIA and parents of children with arthritis.

Table of Contents

An Overview	5
What is Arthritis?	6
What Causes Juvenile Idiopathic Arthritis?	7
Diagnosis	8
Unique Features of Juvenile Idiopathic Arthritis	9 - 10
• Growth	9
• Eye Problems	9
• Unpredictability	10
Patterns and Types of Arthritis in Childhood	11 - 14
• Oligoarticular-persistent JIA, Oligoarticular-extended JIA, Polyarticular-RF negative JIA, Polyarticular-RF positive JIA, Systemic JIA, Enthesitis-Related-Arthritis, and Psoriatic Arthritis	
What Will Happen to Your Child?	15
Treating Juvenile Idiopathic Arthritis	16 - 26
• Medications: Non-Steroidal Anti-Inflammatory Drugs, Aspirin, Steroids (Cortisone-Type Drugs including joint injections), Disease-Modifying Anti-Rheumatic Drugs and Biologic Agents	16
• Newer Therapies	20
• Physiotherapy and Occupational Therapy	21
• Active Exercises	22
• General Physical Activities	23
• Splinting	23
• Rest	24
• Relief of Morning Stiffness	24
• Improvement Takes Time	24
• Eye Care	25
• Surgery	26
Your Family and Juvenile Idiopathic Arthritis	27
Independence and Learning to Cope With Life	28
Your Child and School	28
Adolescence	30
Aims of Therapy	30
A Word of Encouragement	31
Research	32
Alternative Therapies	33
A Note to Parents	33
Common Arthritis Terms	34 - 36

An overview

“Arthritis is not just a disease of old people.”

Arthritis is not just a disease of old people. In fact, approximately 1 in 1,000 children under the age of 16 suffers from arthritis, making the disorder more common than most chronic childhood disorders, including cystic fibrosis and diabetes. Previously, chronic childhood arthritis was referred to as juvenile rheumatoid arthritis (JRA) but arthritis in children is quite different from adult rheumatoid arthritis and is not always associated with the presence of an arthritis associated autoantibody known as the rheumatoid factor. As a result, many people now refer to chronic childhood arthritis as juvenile idiopathic arthritis or JIA. Idiopathic simply means “unknown” and is used when other known illnesses known to cause arthritis are ruled out such as infections, injuries, cancers, and other related rheumatic/autoimmune disorders (lupus, dermatomyositis, vasculitis). While research has not yet provided us with a cure for childhood arthritis, there is effective therapy. Children who are followed closely, monitored carefully and adhere to the recommended treatment provided by a multidisciplinary team do best overall and most are able to participate in normal activities and have a bright future. Expanding research initiatives and the availability of more effective medications will allow us to do even better with this disease.

Once your child has been diagnosed as having arthritis, the overall treatment plan will be coordinated by your child’s doctor, and will include medication and rehabilitation therapy. An exercise program, specially designed by your child’s doctor and therapists, is one of the cornerstones of treatment.

Even if arthritis does cause joint damage, the bones and cartilage of growing children have amazing abilities to heal. Exercise helps prevent loss of joint movement and encourages normal growth.

The medication prescribed by your child’s doctor acts to reduce joint swelling, pain and stiffness, prevent joint damage and makes the exercise program easier for your child to do. The choice, nature and strength of the medication will depend on the severity and type of arthritis.





What is arthritis?

Terms ending in “itis” refer to swelling or inflammation of a part of the body. “Tonsillitis,” for example, refers to red, inflamed, painful tonsils. The term “arthritis” means swelling and inflammation of the joint lining. In JIA, this inflammation results in warm, stiff, swollen and often painful joints. It is important to know that not all joint pain is arthritis. Joint pain without inflammation, or arthralgia, is quite common and can occur in many conditions.

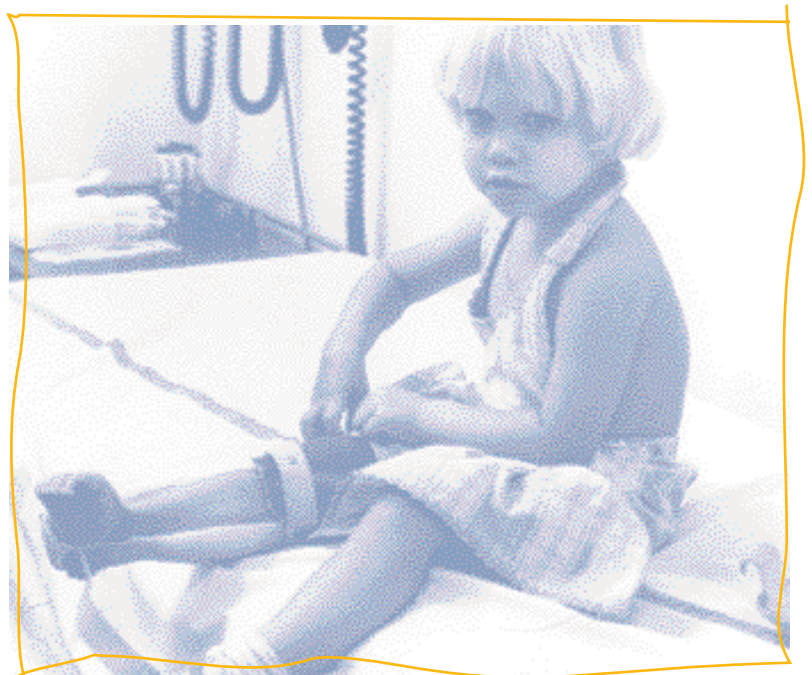
A capsule encloses the joint space between two bones. The inner lining of this capsule, the synovium, produces a fluid that lubricates and nourishes the joint. The ends of the bones are covered with a smooth substance called cartilage, which allows the bone ends to glide smoothly across each other. In arthritis, imbalances in the immune system cause the synovium to become inflamed and thickened, producing extra fluid, which contains inflammatory cells. Inflammatory cells produce and release substances that can cause the symptoms of joint inflammation (warmth, stiffness, swelling, pain) and, if left untreated, also lead to damage of the cartilage and underlying bone.

What **causes** Juvenile Idiopathic Arthritis?

No one knows. We do know that most subtypes of JIA do not run in families, and arthritis is almost never passed from a parent to a child. Therefore, the chances of your child passing arthritis on to his/her children would be extremely rare. JIA is not caused by any disease or infection that either parent may have had at any time, nor is it connected to any event during pregnancy. JIA is not caused by eating the wrong foods, nor is there any proof that it can be improved by specific diets. Similarly, although many people feel that their arthritis is better in warm, dry climates, there is no scientific proof that JIA is caused or improved by any particular climate.

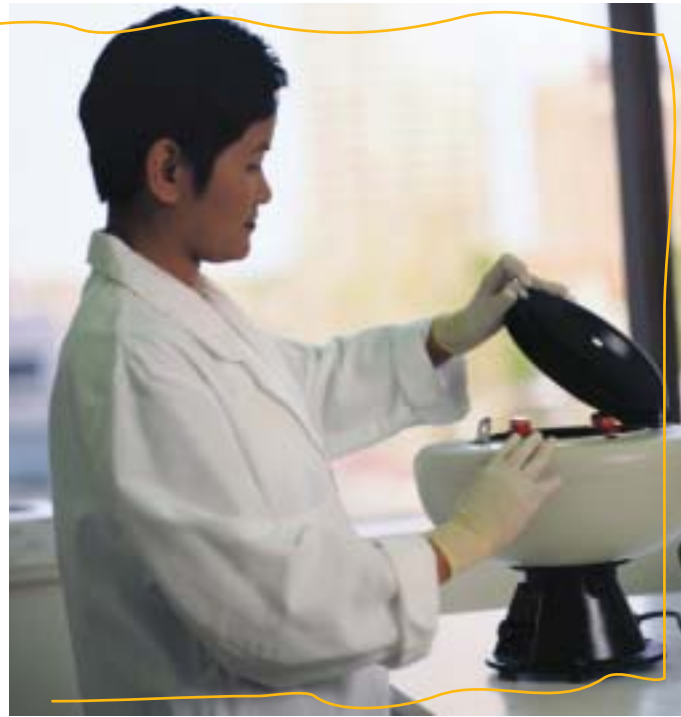
The onset of JIA may follow a routine infection or injury, but such common events do not cause chronic arthritis. It is currently believed that the body's immune system may be responsible for the inflammation. The body's immune system is a complex and finely tuned defence mechanism, which fights infection by causing inflammation, as it does in tonsillitis. Tonsillitis is caused by an infection, and the sore, red, inflamed tonsils are signs that the body's immune system is acting normally to eliminate this infection. In juvenile idiopathic arthritis, there is also inflammation of one or more joints, but in contrast to tonsillitis, we do not know what causes this inflammation. In children with arthritis, the immune system seems to be overactive. It may respond inappropriately to infection or mistakenly identify something in the body for an infection, causing continuous inflammation.

Although fever and rash may occur in some children with arthritis, juvenile idiopathic arthritis is definitely not contagious.



Diagnosis

Children with arthritis do not always complain of pain. As a result, it may be hard to tell if a child's joints are inflamed. Sometimes the only initial clue to arthritis may be that the child is stiff upon awakening in the morning or after a nap, and walks with a limp, or has some difficulty using his or her arm or leg. Rarely, there may be no signs other than a swollen joint or some movement loss when the child is examined. Juvenile idiopathic arthritis can be difficult to detect and may sometimes go unrecognized by even the most experienced physician. Your child's doctor will look carefully for any signs of joint swelling or loss of mobility, which indicate that the joints are inflamed.



Juvenile idiopathic arthritis is defined as continuous inflammation of one or more joints lasting at least six weeks for which no other cause can be found in a child 16 years of age or younger. Since arthritis may be a part of many different illnesses and there is no test that can definitely diagnose juvenile idiopathic arthritis, tests to exclude other causes of joint pain and swelling must be done. Therefore your child will likely require X-rays and blood tests. Laboratory tests may also help in classifying your child's type of arthritis and determining if your child is at risk of more severe disease. This may include testing for the autoantibodies such as rheumatoid factor (RF) and anti-nuclear antibody (ANA). In addition, once the diagnosis of JIA is confirmed, tests will need to be repeated from time to time to monitor the illness and the effects of medication.

The uncertainty and doubt of the first several weeks following discovery of the arthritis can result in an emotionally difficult time for you, your child and your family. It is important for you to realize that it may take time for your child's doctor to be absolutely certain of the diagnosis of juvenile idiopathic arthritis. You must also understand that it may take up to several weeks or sometimes even months for the medicines and exercises the doctor prescribes to have a noticeable effect.

Unique Features of Juvenile Idiopathic Arthritis

Growth

One of the unique issues in JIA is the effect of inflammation on the growing child. There may be local changes in the growth of individual joints that have been affected by arthritis. Inflammation can lead to accelerated growth. For example, knee inflammation may cause the leg to grow slightly faster than the non-inflamed side. The growth usually returns to normal once the arthritis has improved. Occasionally, if the inflammation is not well controlled, a slowing of growth may occur. For example, ongoing jaw inflammation may result in a small chin. Some-times, if the arthritis is severe and requires medications such as steroids, a generalized slowing of growth may occur. The growth will usually return to normal once the arthritis is controlled and the steroids are tapered or stopped. The health care team will pay careful attention to all aspects of your child's growth.

Eye Problems

Sometimes a child with JIA may suffer from inflammation inside the eye. This eye disorder goes by many names such as: uveitis, iritis, iridocyclitis, anterior uveitis, and nongranulomatous iritis. This inflammation often occurs without symptoms or visible signs so that you and your child may not be aware of its presence. Therefore, it is important for the child's eyes to be checked regularly, even if they are not red or painful. In the early stages, this inflammation can only be detected by a special examination (slit lamp examination), which must be done by an ophthalmologist (a physician specially trained in eye care and treatment) or an optometrist (a non physician who has special training in performing eye examinations).

“Inflammation often occurs without symptoms or visible signs”





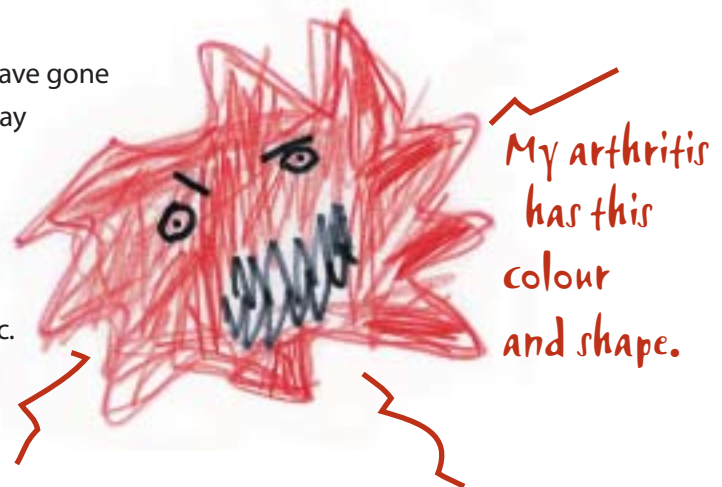
If your child develops uveitis, then your child should be under the care of an ophthalmologist to receive appropriate treatment. Your child's doctor will make sure that regular eye examinations are arranged to follow your child. Undetected, or inadequately treated uveitis can lead to cataract (a cloudiness in the lens of the

eye), glaucoma (high pressure inside the eye), and/or band keratopathy (calcium deposition on the surface of the eyeball) all of which can lead to vision loss or even blindness. Sometimes scar tissue forms at the edge of the pupil (called posterior synechiae) causing the pupil to be irregular in shape rather than the normal circle. Although this does not affect vision, it is a sign that there is or has been active uveitis. It is desirable to identify ongoing inflammation before synechiae occur. For more information about the complications of uveitis, visit the website of the Pediatric Glaucoma and Cataract Family Association (www.pgca.org). The uveitis is not related to the degree of inflammation in the joints. Eye disease is, in fact, most common in children with only one or a few joints involved; it may even start before arthritis is diagnosed. Although uveitis can occur in any form of JIA it is most common in ANA positive, rheumatoid factor negative, young girls with oligoarticular JIA and older boys with polyarticular JIA. It can start in one or both eyes. If after 6-12 months the uveitis affects only one eye, it is unusual for the uveitis to then affect the other eye, but ongoing regular visits to an eye doctor are essential. Some children have only one episode of uveitis that easily responds to treatment. Others may have recurrent uveitis that responds to treatment each time with periods of no inflammation in between bouts. A minority of children (approximately 10% of those with uveitis) will have chronic ongoing uveitis that may require months or years of treatment. These latter children are the ones most at risk for other eye complications and vision reduction.

Unpredictability

Arthritis in children sometimes may last for as little as several months to a year and then disappear forever. Most children, however, have an up-and-down course for many years, depending on what type of arthritis they have. Flares (also known as flare-ups or exacerbations) are those times when the arthritis seems to be getting worse. Some children may continue to have arthritis that extends into adulthood.

Remissions are times when the arthritis appears to have gone away. Sometimes, a mild infection, such as the 'flu,' may cause a flare. Usually, the reason for the flare is not identified. It may be upsetting for parents to see such changes when it seemed the disease had disappeared or had improved. Nevertheless, parents should not give up hope and should remain optimistic. Fortunately for most children, these flares tend to become less severe and occur less often with time.



Patterns and Types of Arthritis in Childhood

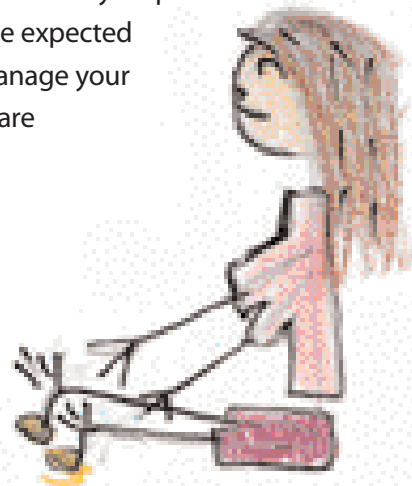
There is great variation in both the symptoms and nature of childhood arthritis. Therefore, once a doctor has diagnosed or questioned arthritis in your child, referral to a specialist, such as a pediatric rheumatologist (a physician specially trained in diagnosis, evaluation and treatment of disorders of joints, muscles and bones in children), will usually be required. A specific diagnosis is important and necessary so that a specific treatment program can be designed for each individual child.

There are 7 major subtypes of JIA:

- Oligoarticular – persistent JIA
- Oligoarticular – extended JIA
- Polyarticular – RF negative JIA
- Polyarticular – RF positive JIA
- Systemic JIA
- Enthesitis – related arthritis (ERA)
- Psoriatic arthritis

The subtype of JIA assigned for your child's arthritis is largely based on information at the start of the disease (physical examination findings, laboratory and imaging tests) but also on what happens with your child's disease course over the next 6-12 months. It is important for you to realize that it may take time for your child's doctor to be absolutely certain of the subtype of JIA and sometimes if your child's disease course changes, a different but more appropriate subtype will be assigned for your child's JIA. However, the initial management of your child's arthritis will not be hindered or delayed by not having a confirmed subtype of JIA available. Knowledge of the subtype of JIA will ultimately help to provide information to you, your child and health care providers about the expected disease course and to design a treatment plan specially customized to manage your child's arthritis. The common features for each of these types of arthritis are summarized on the following pages.

On a bad day, my arthritis hurts.



Oligoarticular – Persistent Juvenile Idiopathic Arthritis

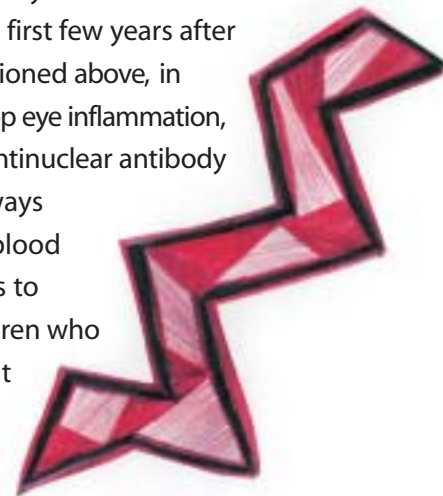
This is the name given to the most common and generally mildest form of juvenile idiopathic arthritis. Oligoarticular (and sometimes called pauciarticular) means involvement of few joints (4 or fewer joints). Children are classified as having oligoarticular – persistent JIA if beyond 6 months after the initial start of arthritis, there is involvement of no more than 4 different joints throughout the course. Girls are affected much more commonly than boys. It usually starts in children four years of age or younger. The most commonly affected joints are the knee, ankle, wrist and elbow. There is little or no disturbance of general health or growth. The course of oligoarticular-persistent JIA may involve flares and remissions, but with appropriate treatment, there is rarely permanent damage to the joints. In fact, many affected children will be in permanent remission within a few years after the onset of the disease.

Up to 20% of children with oligoarticular-persistent JIA will eventually develop uveitis. Therefore, all children with oligoarticular JIA should have a regular, routine slit-lamp examination of their eyes at least three or four times a year for the first few years after diagnosis. In children who develop eye inflammation, the blood test for antinuclear antibody (ANA) is almost always positive. The ANA blood test therefore helps to identify those children who will require frequent eye checks.

Oligoarticular – Extended Juvenile Idiopathic Arthritis

As described above, oligoarticular means involvement of few joints (4 or fewer joints). However children are classified as having

oligoarticular – extended JIA if there is involvement of 4 or fewer joints within the first 6 months after the initial start of arthritis, but beyond 6 months of the disease course, the child goes on to develop arthritis in new locations resulting in 5 or more joints being affected in different locations anytime throughout the disease course (remember that not all joints need to be active at the same time but importance is placed on the number of different locations of joints affected). Large and small joints may be affected. The course of oligoarticular-extended JIA may involve flares and remissions, but with appropriate treatment, permanent damage to the joints can usually be prevented. Associated eye disease can also be present and children should also have a regular, routine slit-lamp examination of their eyes at least three or four times a year for the first few years after diagnosis. As mentioned above, in children who develop eye inflammation, the blood test for antinuclear antibody (ANA) is almost always positive. The ANA blood test therefore helps to identify those children who will require frequent eye checks.



Polyarticular – Rheumatoid Factor Negative Juvenile Idiopathic Arthritis

Children with polyarticular-RF negative JIA have many joints (five or more) involved within the first 6 months of disease but without a positive blood test for rheumatoid factor (RF). This type of juvenile idiopathic arthritis can begin at any age, and usually, the arthritis starts in several joints at the same time.

It is more common in girls than in boys. Occasionally it will begin in only one or two joints, then spread to other joints. Of special note, two joints that may become involved in this type of JIA are the temporomandibular joint (TMJ) and the cervical spine (neck). TMJ arthritis can lead to limited jaw opening and affect chewing as well as cause abnormal growth of the jaw leading to a small chin. Your child's doctor will check if these two joints are affected (physical examination and X-rays when indicated) and inform you and your child of any further management and precautions if necessary. The duration of polyarticular JIA varies from six months to many years. In general, the arthritis runs a course that lasts several years. Interference with growth is less of a problem in polyarticular JIA than it is in systemic JIA, and inflammation of internal organs is rare.

Polyarticular – Rheumatoid Factor Positive Juvenile Idiopathic Arthritis

Children with polyarticular-RF positive JIA have many joints (five or more) involved within the first 6 months of disease associated with a positive blood test for rheumatoid factor (RF). This type of juvenile idiopathic arthritis can begin at any age, however, onset frequently occurs with older girls. Usually, the arthritis starts in several joints at the same time. The onset of polyarticular-RF positive JIA in teenagers may closely resemble adult rheumatoid arthritis (RA). It is more common in older girls than in boys. Occasionally it will begin in only one or two joints, then spread to other joints. It can affect both the small (especially hands and fingers) and large joints (knees, hips, ankles) usually on both sides of the body. Some children may also have additional findings such as a low-grade fever, rheumatoid

nodules (bumps under the skin), anemia (low red blood cell count or fall in hemoglobin level), significant fatigue, poor appetite and general unwellness. This type of JIA has a greater tendency to cause severe joint damage than other types of arthritis. Thus, stronger medications are recommended at an early stage for children with polyarticular-RF positive JIA.

Systemic Juvenile Idiopathic Arthritis

This form of JIA affects the body generally with fever and can affect the child's internal organs as well as joints and skin. Systemic JIA can begin at any age and affects boys and girls equally. It usually involves many different joints and some joints may have severe disease. Children with systemic JIA have spiking (rapidly rising and falling) fever, which usually occurs once (or sometimes twice) a day, and a rash that frequently comes and goes with the fever. The rash usually appears as pale red spots on the child's chest, upper arms, thighs and other parts of the body. In addition, they often have swollen lymph glands, and enlargement of the liver and spleen. They appear listless and unwell during the fever (most often in the late afternoon or evening), only to brighten up by the next day as their temperature returns to normal. When fever in systemic JIA persists for several weeks, the child will be weak, lose weight and may become pale from anemia (a fall in the level of hemoglobin in the blood). Flares that last a long time may also interfere with growth, although the growth usually improves as the child's condition improves.

Inflammation of internal organs may cause stomach pain or affect the heart or lungs but will not cause permanent damage.

“even severe forms of arthritis sometimes go into remission within a few years”

In the early stages of systemic JIA, there is sometimes no sign of joint inflammation. This may make it a very difficult disease to diagnose because there are many other illnesses that also cause a fever and rash in children. Therefore, many tests are done. The arthritis usually appears within the first six months after the start of the fever, and usually persists, even when the fever settles. The arthritis may be mild or severe, and may involve just a few, or many joints. However, even severe forms of arthritis sometimes go into remission within a few years. If the arthritis does not go into remission, it will follow a pattern of “ups and downs” that is different for each child. In most cases, the pattern will gradually become less severe. Occasionally, as with all forms of JIA, flares may occur after the disease has been inactive for a long time.

Medications used to treat children with systemic JIA will include drugs that control not only the arthritis but also the systemic part of the illness, such as the fever and anemia. Uveitis is uncommon in systemic JIA but children should still have their eyes examined annually.

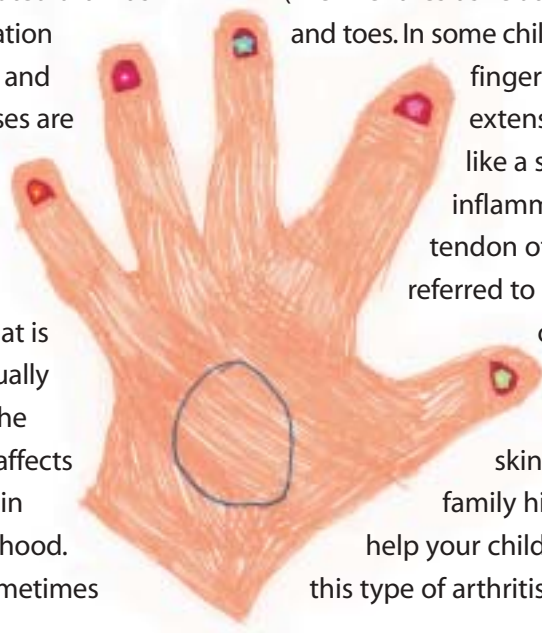
Enthesitis – Related – Arthritis

Children with enthesitis-related-arthritis (ERA) demonstrate inflammation both in their joints (arthritis) and entheses (enthesitis). Entheses are spots where tendons attach or insert into bones. This type of JIA generally affects children over the age of 10, and is the only type of JIA that is more common in boys. It usually involves just a few joints in the lower limbs and commonly affects the hips. Joint inflammation in ERA often persists into adulthood. This form of arthritis may sometimes

progress to involvement of the spine or sacroiliac joints and lead to pain and stiffness of the back. Entheses in the lower limbs are usually affected, especially around the knees, ankles and bottom of the feet, and therefore children may often complain of knee, heel or foot pain particularly with activity. ERA is one of the few types of arthritis that may be hereditary or run in families. It may also occur with inflammation of the eyes, or bowel, either in the patient or in other family members. Many children with ERA carry a protein called HLA B-27 on their cells. Testing for this protein in the laboratory may help in the diagnosis in some cases.

Psoriatic Arthritis

Psoriasis is a skin disease that is accompanied by arthritis in many cases. Psoriasis appears as a scaly red rash usually on the scalp, behind the ears, on the eyelids, elbows, knees, buttocks or in the belly button. Some children may also have changes on their fingernails (pitting or ridging). When arthritis and psoriasis occur together, the disease is called psoriatic JIA. This type of arthritis can occur at any age affecting both boys and girls. It often affects only one or a few joints but may also involve the hips or back (like in enthesitis-related-arthritis), or the fingers and toes. In some children, the swelling in the fingers or toes may be so extensive that the digit appears like a sausage. This is due to inflammation and swelling in the tendon of a finger or toe and is referred to as dactylitis. In about half of children with psoriatic arthritis, the arthritis starts before any sign of skin disease. For this reason, a family history of psoriasis will help your child’s doctor to diagnose this type of arthritis.



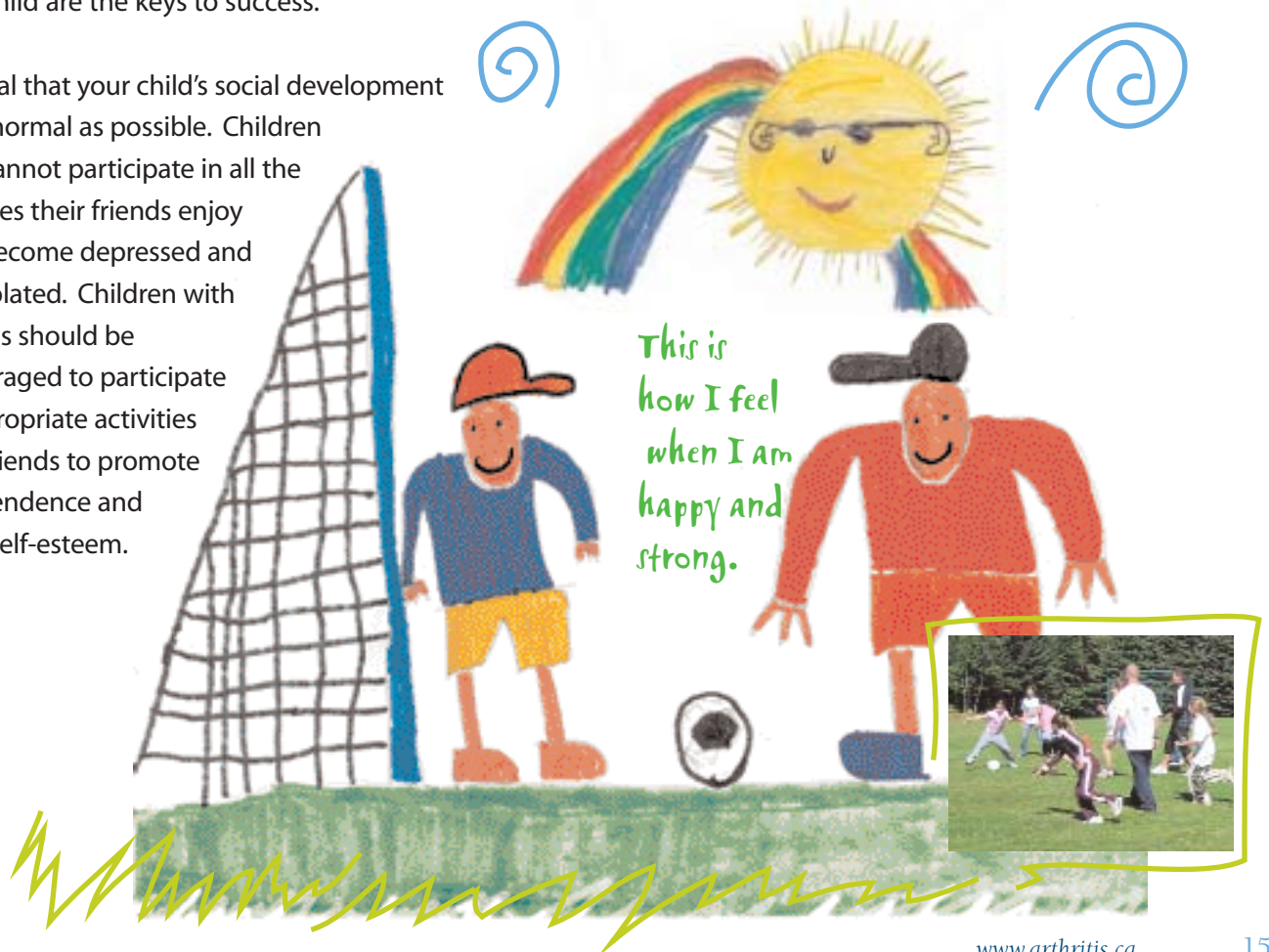
What will **Happen** to your Child?

Although the long-term outlook for most children with arthritis is usually good, it is impossible to predict exactly what will happen to your child. It is true that the longer the disease remains active, the greater the risk of joint damage. Once your child has established a pattern of disease, your health care team will be able to give you a general idea of the future.

To achieve the best possible outcome, you and your child will need to work very closely with the arthritis treatment team. This may include your child's doctor, a nurse, a physiotherapist, an occupational therapist, a social worker, psychologist, dietician, an orthopedic surgeon, an ophthalmologist (or optometrist if your child does not have active uveitis or related eye problems needing treatment), a dentist and your child's teachers. The specific members of the team involved in the care of your child will be determined by the nature of the arthritis and his or her special needs. The most important members of the team are you and your child. With help and guidance of the team, your child can deal with even severe arthritis.

The attitude and emotional response of a child and his or her family are extremely important in determining the future. Some joints may be damaged because of inflammation, but an exercise program and the use of splints can help to prevent deformities. It may take time to notice the benefits of therapy. Persistence with the suggested treatment and a positive attitude from you and your child are the keys to success.

It is vital that your child's social development be as normal as possible. Children who cannot participate in all the activities their friends enjoy may become depressed and feel isolated. Children with arthritis should be encouraged to participate in appropriate activities with friends to promote independence and build self-esteem.



Treating Juvenile Idiopathic Arthritis

Medications

As yet, there is no cure for juvenile idiopathic arthritis. Still, there are medications that can reduce the inflammation, relieve pain and swelling associated with arthritis and help make exercise programs more effective as well as prevent or minimize permanent joint damage. To be fully effective, medication must always be taken regularly and exactly as prescribed. A medication program will be designed by your child's doctor specific for your child. Remember that children's medications are prescribed according to the child's weight and disease activity. It is important to take the medication as prescribed and not to change the dosage without the doctor's knowledge.

Aspirin

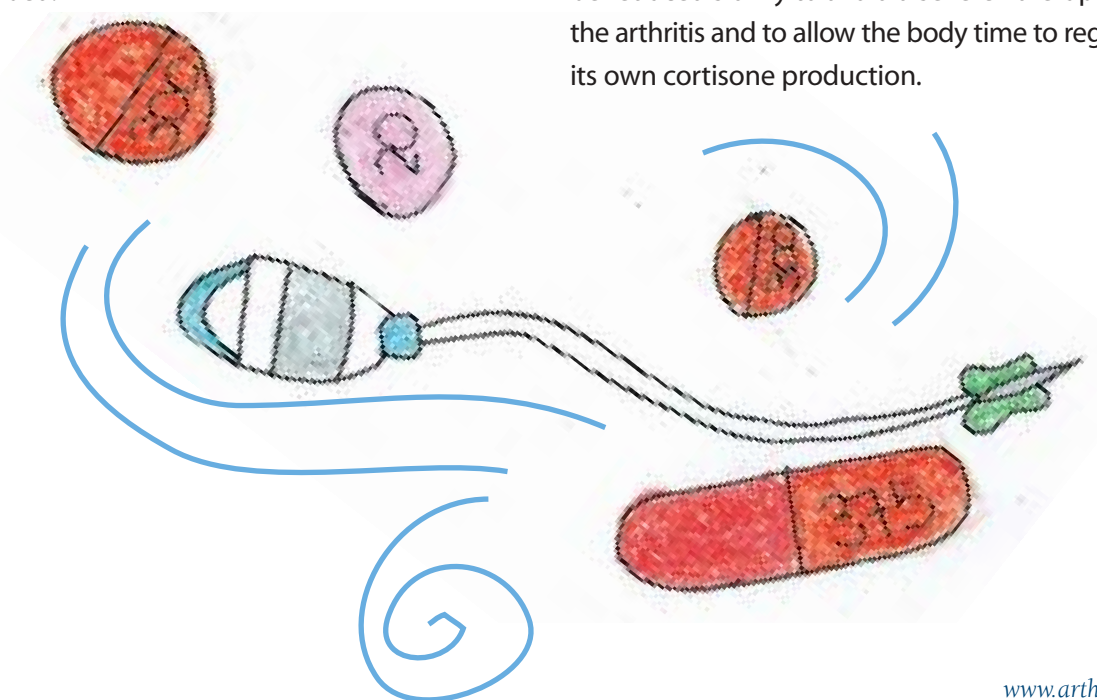
Aspirin® (also referred by generic names; acetylsalicylic acid or ASA) used to be the most commonly prescribed drug for juvenile idiopathic arthritis. Although it remains a safe and effective drug for many children with JIA, and continues to be used by rheumatologists, some of the other NSAIDs are more convenient to take and are often better tolerated than aspirin. In children taking aspirin there is a very small risk of Reye's syndrome (sudden onset of altered state of consciousness together with liver disease) following infection with chickenpox or influenza. If you are concerned you should ask your child's physician for advice.



Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

Most treatment approaches will start with anti-inflammatory medications. This includes a variety of medications that decrease the processes involved in inflammation. However, these medications do not contain cortisone (steroids) and therefore are referred to as Non-Steroidal Anti-Inflammatory Drugs (NSAIDs). By reducing pain, swelling and stiffness, these drugs alone often allow a child with arthritis to participate in normal day to day activities. NSAIDs do not cause addiction, and their effect on inflammation does not wear out over time.

Some of the more commonly prescribed medications in this group include naproxen, indomethacin, ibuprofen and others. The choice of medication is based on disease type, how easy it is to take and physician preference. Sometimes it may take up to 8-12 weeks to see improvement. Sometimes one NSAID works while another does not, and it may occasionally be necessary to try several NSAIDs to find which one works best for your child. NSAIDs can be available as either a liquid or pill form and are usually given one to four times per day based on the type of NSAID prescribed.



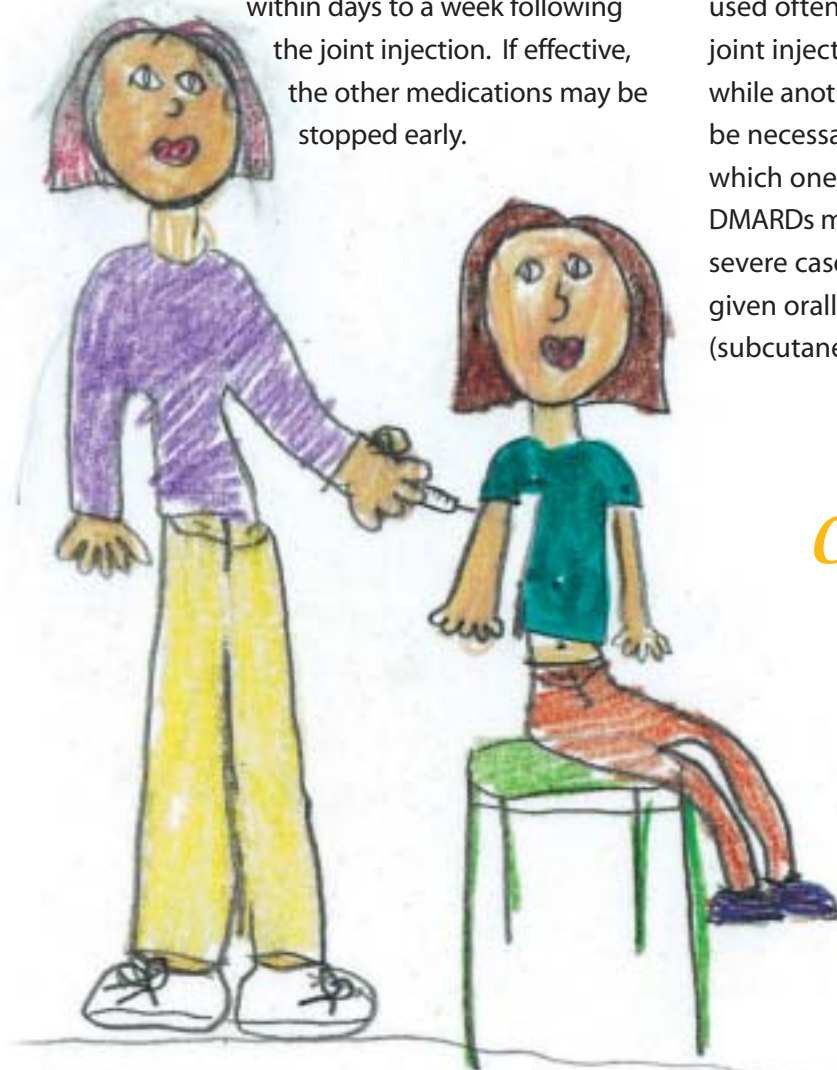
Steroids (Cortisone – Type Drugs)

Cortisone is a steroid hormone produced naturally by the body, and is extremely important for normal body metabolism. Corticosteroids (short term: steroids) are also very powerful drugs against inflammation and improvement can be seen quickly (e.g. as early as 48 hours). It is very different from the anabolic steroids sometimes taken by athletes. Steroids can be given orally, or as an injection through a vein (IV) or into the joint itself. Steroids (oral or IV) are used when the arthritis is severe, has not responded to other drugs or for other especially difficult problems. Prednisone is the most commonly used oral steroid in the treatment of arthritis. Because of its many side effects (see below), prednisone is not prescribed routinely. However, the side effects depend upon the amount and length of time over which the prednisone is used. Often in arthritis, prednisone is used at relatively low doses and for short periods of time until disease-modifying anti-rheumatic drugs (DMARDs) start to work. Every attempt is made to use prednisone in the smallest dose possible for the shortest time possible in order to minimize the side effects. Prednisone cannot be stopped suddenly. It must be reduced slowly to avoid a severe flare-up of the arthritis and to allow the body time to regulate its own cortisone production.

Steroid Joint Injections (Cortisone – Type Drugs)

Injections of steroids directly into a joint (intraarticular) can be very helpful for the child with only a few joints involved or persistent arthritis in joints that do not respond to initial drug treatment. This procedure will be done with attention to your child's age and tolerance for it. The known side effects of steroids taken by mouth do not occur with this type of treatment, and one joint injection does not mean that injections will have to be repeated frequently, if ever again. Careful injection under sterile conditions with local anesthetic has little risk of side effects and may improve the injected joint(s) for months or even longer; the initial improvement is often dramatic occurring

within days to a week following the joint injection. If effective, the other medications may be stopped early.

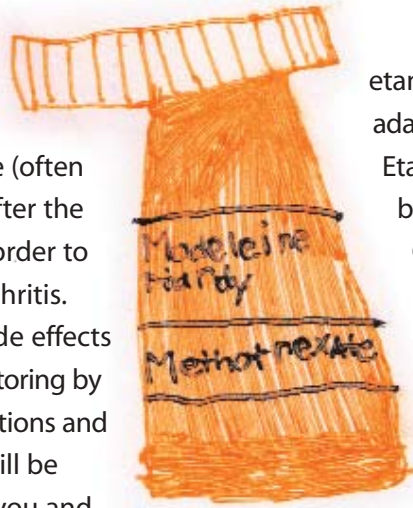


Disease-modifying anti-rheumatic drugs (DMARDs)

For children with prolonged arthritis in several joints or arthritis that is not controlled with NSAIDs or joint injections, continued inflammation within an affected joint may lead to permanent damage, and therefore second line drugs are often prescribed. Drugs in this group include methotrexate, sulfasalazine, hydroxychloroquine, and leflunomide. These agents, also called disease-modifying anti-rheumatic drugs, or DMARDs, are “slow acting” drugs that can take up to six months to work. They are used to obtain better control of the arthritis than that achieved by NSAIDs alone as they stop or reduce the cells in the immune system causing the inflammation. They are used often in combination with NSAIDs and joint injections. Sometimes one DMARD works while another does not, and it may occasionally be necessary to try different DMARDs to find which one works best for your child. Several DMARDs may be combined together to manage severe cases of arthritis. DMARDs can be given orally, or as an injection under the skin (subcutaneously or SC).

Careful injection
under sterile
conditions with
local anesthetic
has little risk
of side effects

With all these drugs, treatment must be continued for a long time (often months to years) even after the disease is controlled, in order to avoid a recurrence of arthritis. Each drug has its own side effects that require careful monitoring by regular physical examinations and laboratory tests. These will be carefully reviewed with you and your child by the health-care team.



Other agents such as cyclosporin (Neoral), azathioprine (Imuran), or cyclophosphamide (Cytoxan) may be used in some forms of JIA when other agents have failed to control the arthritis disease activity.

Biologic Agents

Biotic agents are a new group of drugs that help reduce symptoms and the inflammation that can cause joint damage. Biologics agents are designed to target specific components of the body's immune system, called cytokines, which play a role in the disease process. Biologics are used when other drugs have not controlled the disease adequately. By blocking certain cytokines in the body that play a role in inflammation, biologics can dramatically reduce inflammation and, in some cases, prevent joint damage.

Biologics also work quickly and improvements may be noticed within 1-2 weeks of starting the biologic compared to other JIA medications. Two cytokines known to contribute to inflammation are tumor necrosis factor (TNF) and interleukin-1 (IL-1).

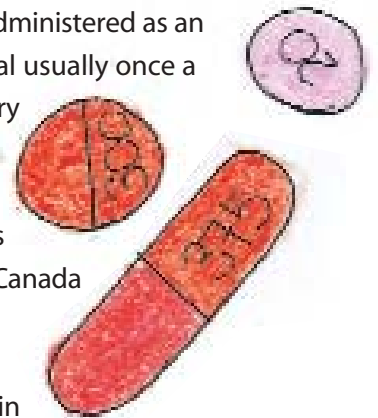
Four biologics are available and approved for the treatment of adult rheumatoid arthritis:

etanercept (Enbrel), infliximab (Remicade), adalimumab (Humira) and anakinra (Kineret). Etanercept, infliximab and adalimumab all block TNF while anakinra blocks IL-1.

Currently, etanercept is the only biologic that is approved by Health Canada for use in children with JIA. Etanercept has been shown to be effective in treating arthritis in children who have not improved on methotrexate alone. It may also be helpful in the treatment of systemic JIA

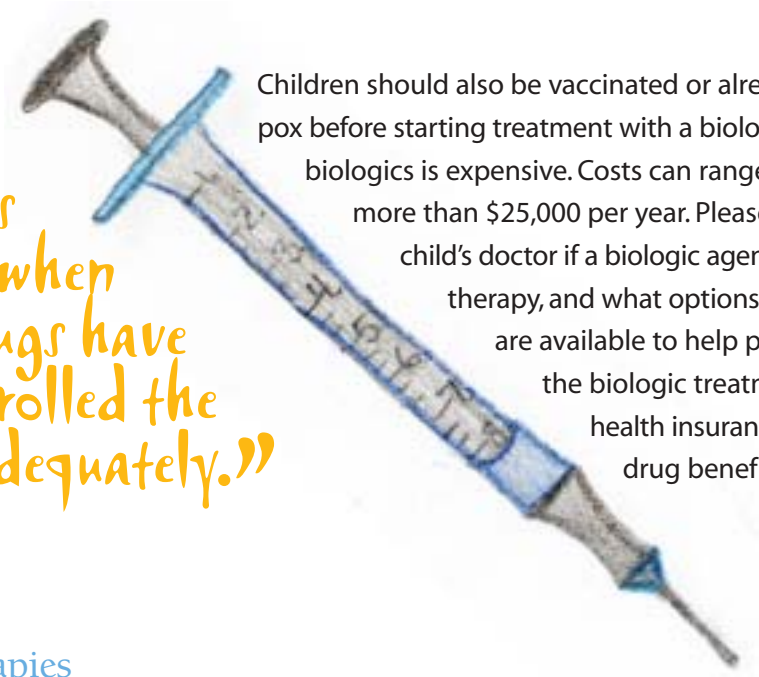
and the uveitis associated with JIA. Etanercept is given as a twice weekly injection under the skin (SC) either alone or in combination with methotrexate and other medications (e.g. anti-inflammatories, corticosteroids). Infliximab works similarly to etanercept but is administered as an IV infusion in a clinic or hospital usually once a month (may vary between every two to eight weeks depending on the child's response and amount of inflammation). It has not been approved by Health Canada for use in children with JIA but preliminary studies in children indicate that it may be helpful in treatment of JIA as well as the uveitis associated with JIA. Adalimumab and anakinra are currently under investigation for use in children. Adalimumab is given as a SC injection once every two weeks while anakinra is given by daily injection.

Prior to the start of any anti-TNF biologic (etanercept, infliximab, adalimumab), your child must be tested to ensure there is no tuberculosis (TB) infection present. This is done by a TB skin test and chest X-ray. Other medical conditions for which it is not safe to give an anti-TNF agent include severe chronic infections, heart failure, neurologic diseases (such as multiple sclerosis, neuropathies), or pregnancy.



“Biologics are used when other drugs have not controlled the disease adequately.”

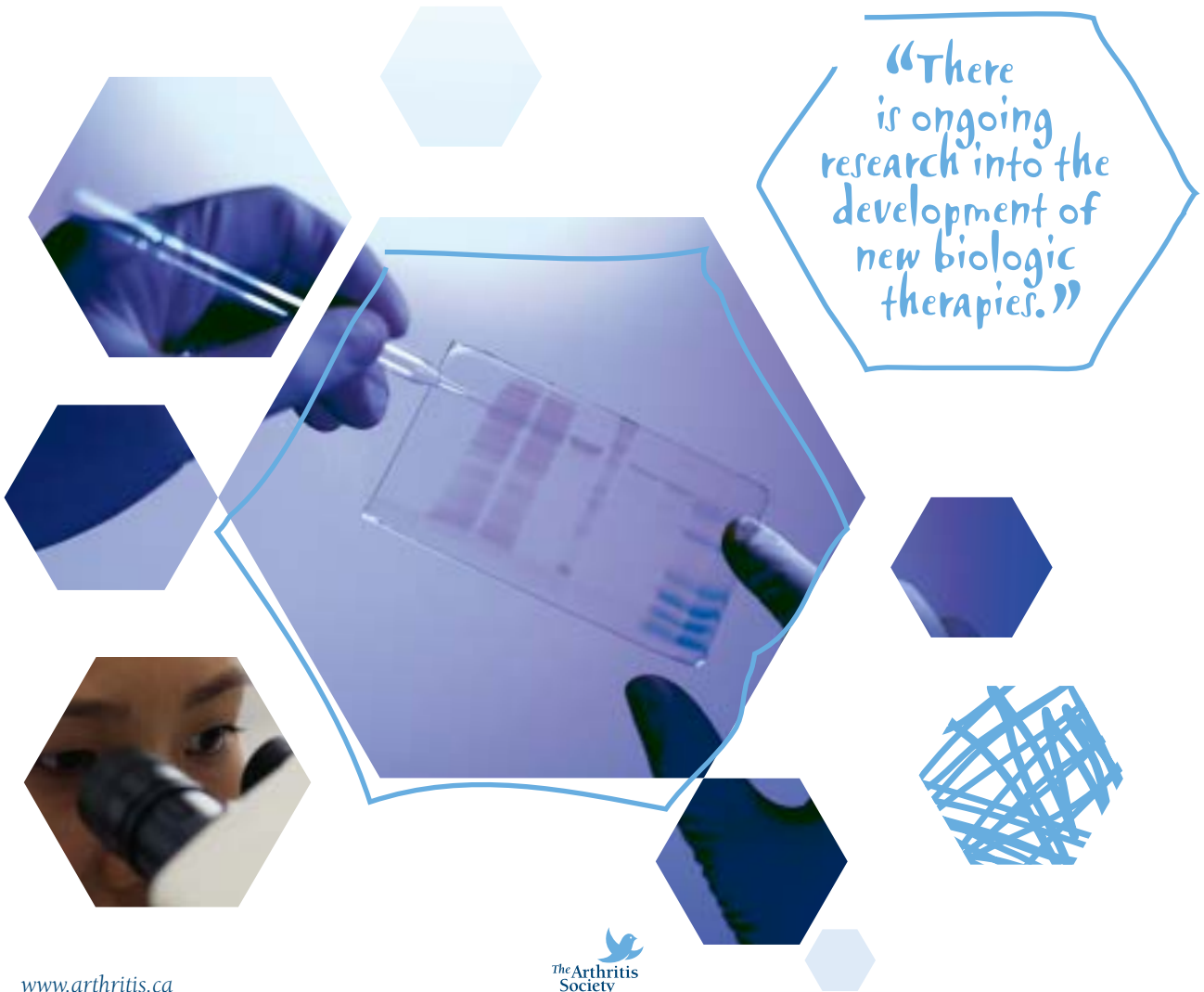
Children should also be vaccinated or already had chicken pox before starting treatment with a biologic. Treatment with biologics is expensive. Costs can range from \$15,000 to more than \$25,000 per year. Please discuss with your child’s doctor if a biologic agent is an appropriate therapy, and what options for drug coverage are available to help pay for the costs of the biologic treatment (e.g. private health insurance plans, provincial drug benefit programs etc).



Newer Therapies

As this edition is going to press, there is ongoing research into the development of new biologic therapies designed to modify the immune response in a precise manner in order to more effectively control the arthritis with less side effects. These include monoclonal antibodies, receptor inhibitors and peptide vaccines. Ask your health care team about these newer agents.

“There is ongoing research into the development of new biologic therapies.”



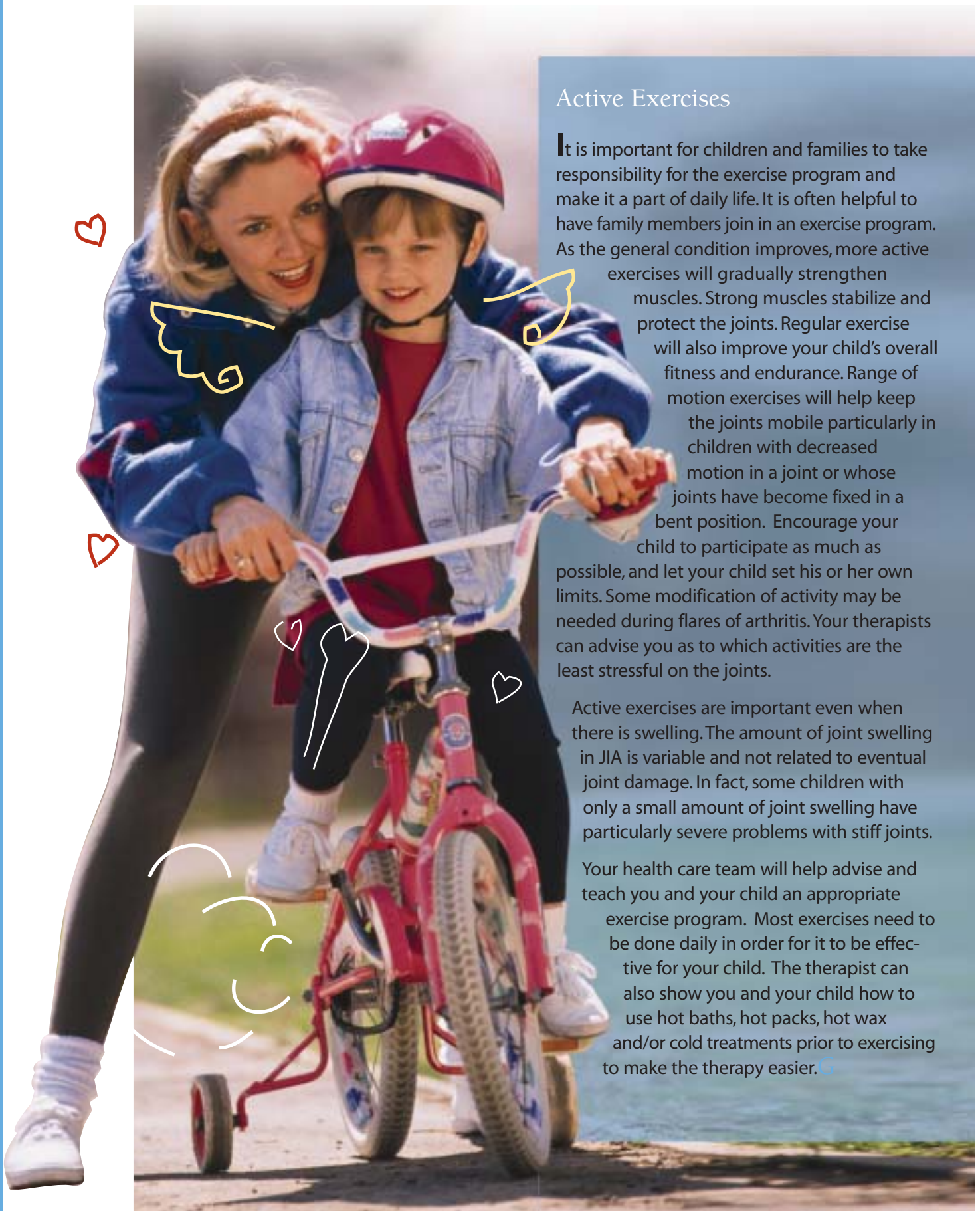
Physiotherapy and Occupational Therapy

Physiotherapy and occupational therapy are essential components of the treatment program for all children with JIA to minimize long-term damage to joints and muscles and to preserve function.

Inflammation causes pressure and sometimes pain in and around the joint, causing muscles around the joint to go into spasm and tighten. Thus, the child with arthritis will tend to keep the inflamed joint(s) in the most comfortable position, which is usually bent. If a joint stays bent for too long, both the muscles and tendons (strong, rope-like structures that attach muscles to bones) will shorten and not grow properly. This results in the joint staying in a bent position, called a joint contracture.

It is very important to remember that in children, unlike adults, cartilage and bone can still grow, which allows for healing and repair of joint damage. However, joint tightness must be reduced by a routine of exercises and splinting; otherwise a deformity may develop, and the child will not be able to completely straighten the joint. If a joint remains in a bent position for too long, it may not grow properly and permanent damage and deformity could result.





Active Exercises

It is important for children and families to take responsibility for the exercise program and make it a part of daily life. It is often helpful to have family members join in an exercise program. As the general condition improves, more active exercises will gradually strengthen muscles. Strong muscles stabilize and protect the joints. Regular exercise will also improve your child's overall fitness and endurance. Range of motion exercises will help keep the joints mobile particularly in children with decreased motion in a joint or whose joints have become fixed in a bent position. Encourage your child to participate as much as possible, and let your child set his or her own limits. Some modification of activity may be needed during flares of arthritis. Your therapists can advise you as to which activities are the least stressful on the joints.

Active exercises are important even when there is swelling. The amount of joint swelling in JIA is variable and not related to eventual joint damage. In fact, some children with only a small amount of joint swelling have particularly severe problems with stiff joints.

Your health care team will help advise and teach you and your child an appropriate exercise program. Most exercises need to be done daily in order for it to be effective for your child. The therapist can also show you and your child how to use hot baths, hot packs, hot wax and/or cold treatments prior to exercising to make the therapy easier. [G](#)

General Physical Activities

Ordinary activities or play are not a complete substitute for a regular exercise program. However, some routine activities are especially good for joint mobility. Even lying flat on the stomach (lying prone) for some time each day will help keep the hips and knees straight. The child may read or watch television in this position. Pre-schoolers are extremely curious, and mobility is extremely important for their development. For these youngsters, riding a tricycle is excellent exercise and can strengthen hips, knees and ankles when walking is too painful. Swimming is also an excellent exercise for most children. With the force of gravity greatly reduced, swimming can improve muscle tone and movement of large joints better than any other activity.

Children with arthritis can be encouraged to participate in sports and recreational activities as tolerated. Recreational activities can help your child to exercise their joints and muscles but can additionally build confidence in their physical abilities, develop social skills and allow them to have fun at the same time. Remember that recreational activities should not replace any therapeutic exercises prescribed by your health care team.

Splinting

The health care team may recommend that your child use splints. Splinting has several purposes in the management of arthritis in children. A splint at night (resting splint) and during naps will hold inflamed joints, such as knees and wrists, in a good position. Resting splints help to prevent, and can gradually correct, deformity.

Sleeping with splints can be at first difficult for some children, who may wake up and complain of pain or discomfort. However, resting splints are generally well tolerated as long as they fit well. They should not cause pain or red marks, and if they do, they must be checked. It is essential that you and your child persevere with the splints. Otherwise your child will tend to sleep in a curled-up position, and since joints gradually stiffen during the night, this could eventually lead to permanent problems.

Daytime splints (working splints) may also have to be worn to support and assist normal daytime activities such as writing. Use of these types of splints can provide pain relief by protecting inflamed joints. Your child may resist wearing splints in front of friends, and it may help to have the teacher discuss the reason for wearing splints with the rest of the children in the class. When your doctor and therapists have decided splinting is no longer necessary, they will advise you on how to stop wearing them.





Children need extra rest when their arthritis is very active, but a child with active inflammation should not be allowed to rest in bed all day as this promotes stiffness and loss of mobility. The mattress should be firm and the top bed sheets should not be tucked in too tight to allow free movement in bed.

Even very ill children should have all their joints moved through as full a range of movement as possible each day. Exercise in a warm pool or in a deep tub bath at least once daily helps the muscles to relax, and allows the joints to be moved in as full a range as possible.

Good posture, even in bed, helps to prevent deformities. There is a right and a wrong way to lie in bed; a therapist can explain the difference. Inflamed joints may be placed in splints to maintain them in a good position. If the neck is involved, only one flat pillow should be used. Larger pillows will encourage the neck to bend forward. Pillows should never be placed under the knees, as this encourages permanently bent knees.

Relief of Morning Stiffness

Most children experience stiffness when they wake up in the morning or after a nap. The stiffness is one of the measures of arthritis disease activity. There are several ways of helping to relieve the stiffness in your child including taking a hot bath or shower, using a hot pack or heating pad, sleeping in a sleeping bag and doing range-of motion exercises. Although most children do better with warmth, some children may respond better to cold treatments (cold pack, plastic bag filled with ice or frozen vegetables).

Improvement Takes Time

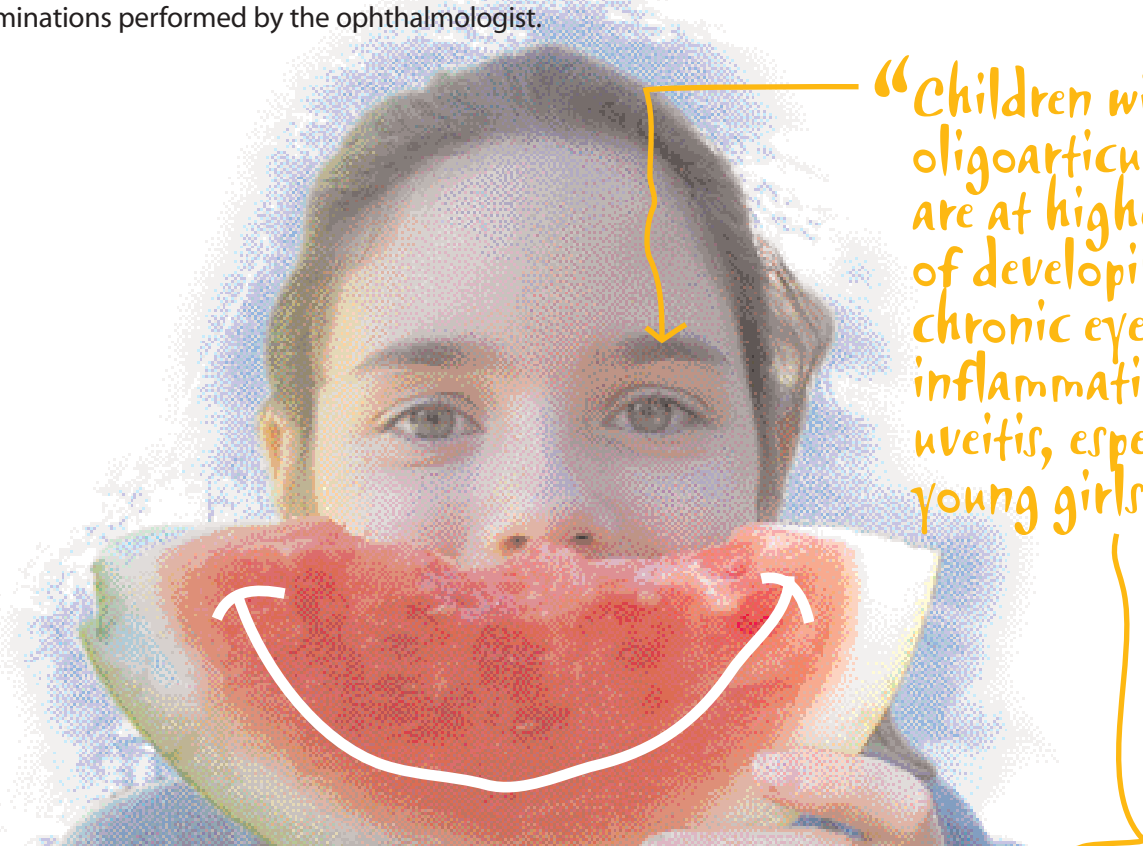
The benefits of exercises will take time. At the start, the exercises may be somewhat painful for your child, and it will be hard for you to constantly remind your child to do them. It will be harder still for you to be consistently positive about the future when your child has had a recent flare. Share your doubts, fears and questions with your child's caregivers. In that way, you and your child will be better able to maintain the positive attitude that is essential for the best possible outcome.

Eye Care

As mentioned previously, eye inflammation can be a unique feature of children with juvenile idiopathic arthritis. Children with oligoarticular JIA are at highest risk of developing chronic eye inflammation or uveitis, especially young girls and those who test positive for the antinuclear antibody (ANA). It is important to realize that children who do not have a positive ANA can still be at risk of suffering from uveitis. Uveitis is least common in systemic JIA. The uveitis most often occurs without any eye symptoms nor changes to the appearance to the eye. Additionally, the uveitis has no relation to the degree of inflammation in the joints. Some patients may complain of sudden onset of extreme pain, redness and light sensitivity in one or both eyes. Although this is a sign of active uveitis or related complications, it does not necessarily mean that the child had uveitis and one should certainly not wait until these symptoms occur. Prompt consultation with an eye doctor is important.

Generally, frequent eye examinations by a trained eye specialist (ophthalmologist or optometrist) are an important part of your child's management to screen for inflammatory problems. If treatment is needed, then the child should be under the care of an ophthalmologist. Prompt treatment reduces the risk for permanent loss of vision. The eye examination, including a slit lamp examination, is a simple and painless procedure except for the eye drops needed to dilate the pupils. These sting for 10-20 seconds. Treatment of uveitis may include eye drops (e.g. steroids, drops to dilate the pupil), injections of steroids behind the eyes (subtenon injections), and other oral or injectable medications discussed previously.

The frequency of the eye exams will depend on your child's risk for developing eye problems and will be determined by your child's pediatric rheumatologist and ophthalmologist/optometrist. Please ensure that you, your child and rheumatologist are informed and updated with the results of the eye examinations performed by the ophthalmologist.



“Children with oligoarticular JIA are at highest risk of developing chronic eye inflammation or uveitis, especially young girls”

Surgery

Surgery is not commonly required but may ultimately be necessary after many years of severe arthritis. Your doctor may seek the advice of an orthopedic surgeon to help plan future treatments and surgical procedures if the need arises to relieve pain, straighten out a bent or deformed joint, restore mobility, or to replace a damaged joint. Sometimes the tendons and ligaments around joints, such as the hips, may need lengthening. When arthritis affects one knee more than the other, the side



with the worse arthritis may grow faster. This may, temporarily, increase the length of the leg of the more involved side, but given time, the growth of the other leg will often catch up. Only very rarely is a surgical procedure required to correct the difference in leg lengths. The orthopedic surgeon may also be asked to make recommendations on splinting and rehabilitation.

If arthritis has severely affected the jaw, there may be poor chin growth. An orthodontist may recommend a splint to be worn in the mouth. Surgical procedures can correct this problem once the disease is in remission. Your doctor may seek the advice of an orthodontist to make recommendations regarding these procedures.

Arthritis of the jaw can make complicated dental work a problem. Be sure to tell your dentist that your child has arthritis so that he or she can give your child's teeth special attention. You should also strongly encourage your child to practice good dental care. As juvenile idiopathic arthritis frequently affects the neck and jaw, it may make general anesthesia difficult, and it is advisable that an anesthetist see children with JIA before any type of operation is planned.

Eye surgery is sometimes needed if a child develops a complication such as a cataract (a cloudiness in the lens of the eye), glaucoma (high pressure inside the eye), and/or band keratopathy (calcium deposition on the surface of the eyeball due to the uveitis).

Your Family and Juvenile Idiopathic Arthritis

Fear of the future can affect how even the strongest family works together. It is very helpful if all family members can become involved in the child's program so that they can provide each other with the support needed to deal with, and overcome, a chronic illness.

Sometimes the parents of a child with a chronic health problem become overly involved with that child to the exclusion of other aspects of their lives. It is important for parents to socialize, maintain their friends and pursue other interests if they are to keep a balanced perspective and provide the optimism and strength their child needs.

The emotional stress of an ongoing illness like arthritis is felt keenly by other children in the family. Brothers and sisters are often confused as to how to feel about the child with arthritis. They want to help, but sometimes – understandably – they are jealous of all the extra attention the child with arthritis seems to receive. Brothers and sisters may have difficulty understanding why there is so little time left for them. Make sure their interests are not overlooked, and encourage them to get involved. It may be appropriate, for example, to have the other children participate in the exercise program with the child with arthritis. Allow them to openly discuss their own efforts and struggles to adjust to their siblings' arthritis. On a positive note, children who grow up in a home with a chronically ill brother or sister often develop rare insight into the problems of others and benefit from this experience.

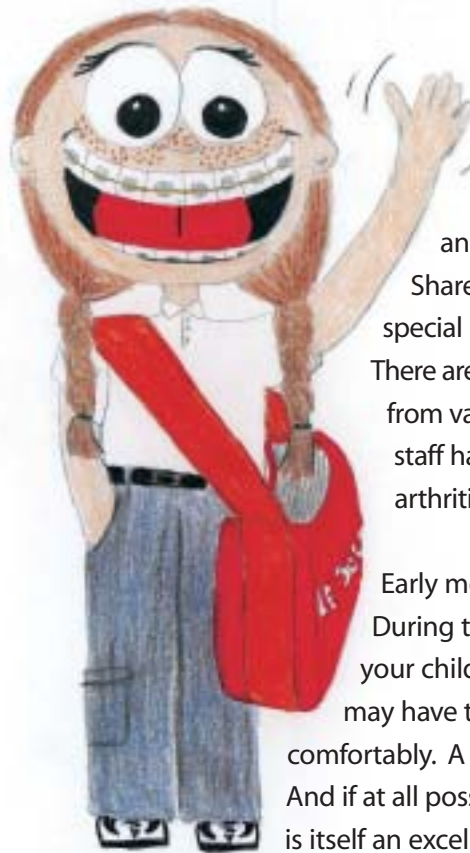


Independence and Learning to Cope with Life

Parents should set limits and discipline the child with arthritis as normally as possible. There is a tendency for parents to excuse the child with arthritis for inappropriate behaviour. However, this may, at times, encourage the child to use the disability for her own advantage both in and outside the home, which can lead to behaviour problems later on in life. Often, parents need help from a professional in knowing how to best deal with some of these issues. A social worker or psychologist skilled in helping families deal with such problems may be of great benefit during these times.

It is important for parents to think in terms of what their child can do and encourage the child to discover his or her own limits from the start. It is important to let your child dress and undress herself, even if this seems to take too long. Involvement of the joints of the hands may make buttons hard to grasp. Often, restricted hip movement can make shoes and socks difficult to put on and take off. An occupational therapist can design aids that will help children manage despite such difficulties.

Your Child and School



It is crucial that your child's life remain as normal as possible.

Attending a regular school should be a prime goal of the treatment program. If the arthritis is active, this will require the encouragement and help of understanding school staff. At the start of the year, set up a meeting with the principal, teachers, nurse and any others in the school who may be in contact with your child.

Share with them your child's condition, limitations, strong points and special needs, and tell them about JIA and your child's treatment program. There are special pamphlets for teachers of children with JIA that are available from various organizations, including The Arthritis Society. If the school staff has further questions, it may be advisable for members of your child's arthritis team to meet with them as well.

Early morning stiffness can be the greatest problem in getting to school. During the night, fluid accumulates in the joints making them stiff. As your child gets moving in the morning the stiffness decreases. Your child may have to wake up early so that the stiffness improves enough to move comfortably. A warm bath with a stretching exercise program is very helpful. And if at all possible, your child should get dressed without help, because dressing is itself an excellent joint exercise.

Since early morning joint stiffness may vary in duration from day-to-day, teachers should be told that your child might sometimes be late. Most children with arthritis attend school full-time, but if your doctor and therapist decide that half-days at school should be tried this may be better done in the afternoons.

Another challenge at school may be the need for frequent eye medications, sometimes as frequently as hourly. No special training is needed to instill eye drops so the school nurse or teachers may do this. Although older children can instill their own eye drops, they may need to be reminded to do so by school personnel. No child should ever miss school solely because of a need for eye drops.

“Since early morning joint stiffness may vary in duration from day-to-day, teachers should be told that your child might sometimes be late”

Classmates will be curious about hand splints. If the teacher treats your child's splints in a matter-of-fact way, so will the class. A simple explanation to the class about the use of splints in the treatment of arthritis is best. Splints can be likened to teeth braces, which are used temporarily to make sure that part of the body grows straight. Painful wrists may make carrying books a problem; the school may provide another set of books for home. A backpack may also be helpful.

Children with arthritis often get stiff if they sit for too long a period of time. Teachers can help by having your child move around in the classroom. If the arthritis is very active, the child may be unable to participate in regular gym classes and arrangements can be made for the child to do physiotherapy during gym. If the knees are very swollen, it is best to avoid sports that require a lot of jumping or jarring movements, e.g. basketball or downhill skiing. However, your child should not be restricted. Unless the arthritis is severe, he or she should be encouraged to participate in activities and set his or her own limits.

It helps to have the classmates of a child with severe arthritis well informed, too. Getting them involved – assisting with boots and clothing, for example, or heavy doors, taking notes and so on – can promote understanding and cooperation, and make your child's school days much easier. Your child may also be able to suggest ways that classmates can help.

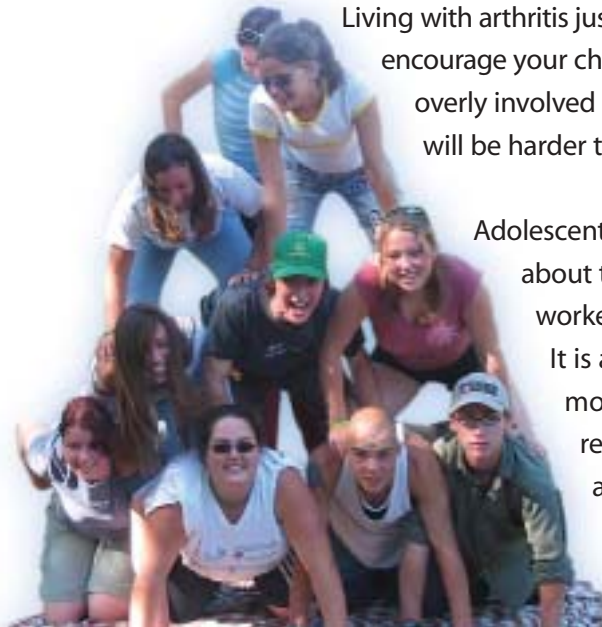
In high school, children are often expected to rotate from class to class. This may pose special problems for children with arthritis. It may be beneficial to have your child excused from class a few minutes early to “beat the rush” to the next class. If possible, try to have classes scheduled so that there is as little distance as possible between different classrooms.

It is important for you and your child to continue to work together with school staff in order for your child to both enjoy and succeed at school.

Adolescence

Adolescence is a particularly challenging time, as one of the main developmental tasks of adolescence is separating from the family and learning to fit in and become independent.

Living with arthritis just adds to the challenges of adolescence. You should encourage your child to pursue and enjoy active friendships. If there is an overly involved relationship between teen and parents, independence will be harder to attain.



Adolescents, like everyone else, need someone to talk to about their problems. Doctors, nurses, therapists, social workers and teachers can help during these difficult years. It is also important to encourage older children to assume more responsibility for taking their medications on time, reporting any joint symptoms or medication side effects, and following an exercise program. These responsibilities will help to prepare them for the transition to adult health care if continued care to manage their arthritis is needed.

Aims of Therapy

Each child with arthritis is an individual with his or her own unique needs and reactions. The treatment program must be designed by the arthritis team – you and your child, the doctor, nurse, ophthalmologist, orthopedic surgeon, therapists, social worker, dietician and teachers, to suit each child. In general, the treatment aims for your child will be to:

- Achieve normal physical, social and intellectual development;**
- Achieve and maintain an acceptable functional range of joint movement;**
- Achieve emotional acceptance of any physical limitations;**
- Attend a regular school;**
- Relate to other children and,**
- Assume responsibility for his/her own health.**



A Word of Encouragement

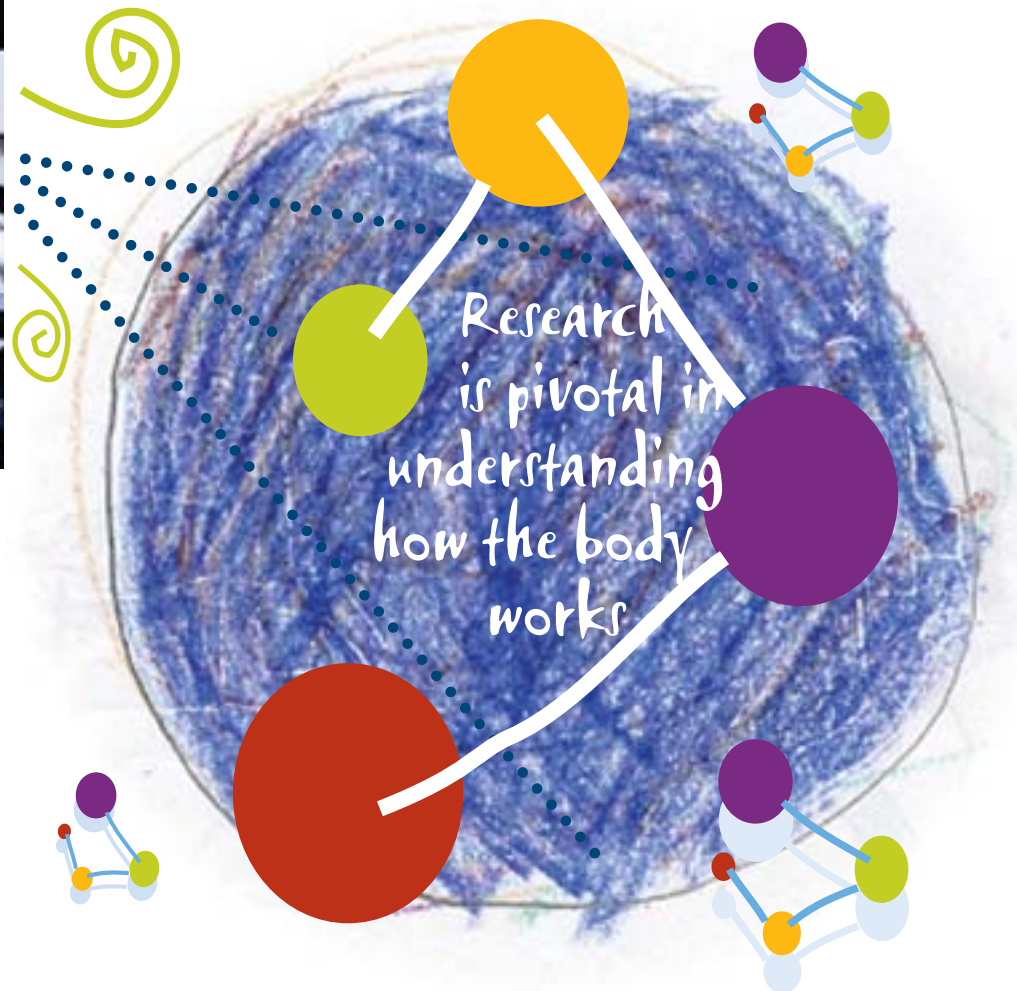
In the majority of children with mild forms of arthritis, it is usually easy to adapt so that there is almost no impact on lifestyle at school or at home. Children with more severe arthritis have to learn to cope with life's difficulties at an early age. They may have to overcome pain, depression, separation from family and friends during hospitalizations and limitations on their ability to do things and have fun. They must take on the responsibility of an exercise program and take medication on a regular basis. But with guidance and encouragement from the arthritis team and the family, these can be growing experiences. The child who has overcome his or her illness grows up to be a unique and special person.



Research

Now, more than ever, advances in research technology are bringing scientists closer to finding causes, cures and perhaps even a form of prevention for juvenile idiopathic arthritis. Not long ago, juvenile idiopathic arthritis was still considered to be a form of adult rheumatoid arthritis. Now that JIA is recognized as a unique disease, research will be even more important. Research is pivotal in understanding how the body works, disease mechanisms, determining the "natural" history of diseases, developing and testing new treatments and helping to improve the quality of life for children with JIA. It is only through research efforts of dedicated individuals that further advances for the care of children with JIA will be achieved. Remember that your child's current care is the result of previous research. Canadian pediatric rheumatologists across the country are at the forefront of many of the research efforts into the causes, management and cures for juvenile idiopathic arthritis. In fact The Arthritis Society funds leading-edge research projects that bring

new insights and lead to new and better treatments for JIA. Ask your health care team about new and ongoing research studies on JIA.



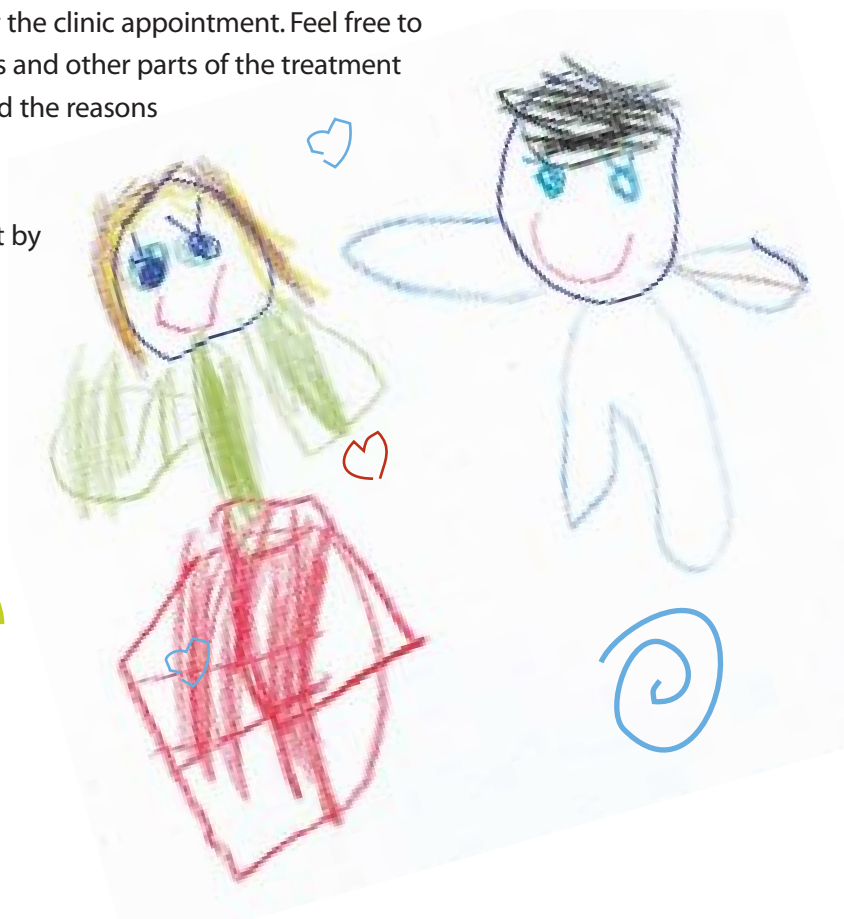
Alternative Therapies

You will frequently hear people swear by many different remedies for arthritis. Some examples include avoidance of certain foods, new medications, reflexology and iridology. Some of these may have merit while others make exaggerated claims of cure. It is understandable that people will elect to try certain forms of, “alternative medicine”, especially when standard medications may not have been extremely helpful. Make sure that your child’s doctor and other members of the health care team are aware that you may be seeking such remedies for your child. They will explore the potential risks and benefits of such approaches and help to ensure that there are no adverse drug interactions with your child’s medications and alternative therapies.

A Note to Parents

Parents are an important part of the overall “team”, and as such, should be as well informed as possible. When you have questions, write them down before the clinic appointment so that they are not forgotten. Please bring or have available a list of all your child’s medications and supplements (including name, dosage, frequency of administration) for the clinic appointment. Feel free to question your doctor about medications and other parts of the treatment plan, and make sure that you understand the reasons behind all the recommendations.

You may also gain a great deal of insight by talking to other families of children with arthritis. Your clinic will likely have various resources from which you can obtain further information about JIA. Your local branch of the Arthritis Society will also be able to provide you with helpful information.



Common Arthritis Terms

I. GENERAL

Arthritis

A word derived from the Greek "arthron," meaning "joint", and "itis," meaning inflammation. Thus, arthritis means inflammation of one or more joints.

Cartilage

Smooth glistening structure that lines the ends of bones and allows them to glide smoothly.

Enthesitis-Related-Arthritis

A form of JIA in which arthritis is associated with inflammation of entheses (where tendons insert /attach to bones) or enthesitis. Usually affects boys over the age of 10 and can affect the back.

Flare (or exacerbation)

The term used for those times when arthritis is at its worst. Flares are common during juvenile arthritis, but usually become less severe over time.

Immune System

The body's defense system against infection; it is overly active in some forms of arthritis. It may respond inappropriately to infection or mistakenly identify something in the body as an infection, causing continuous inflammation.

Inflammation

A bodily response to injury characterized by redness, swelling, heat and pain. JIA involves inflammation of the joints that is not caused by any injury or known infection.

Joint

The site where two or more bones meet, binding the bones firmly together and permitting movement between them. A joint may be a hinge (elbow or knee) or a ball-and-socket (shoulder or hip). The ends of the bones are covered with cartilage so they can glide over each other

easily. Most joints are surrounded by a thin lining (synovium). In arthritis, this lining becomes inflamed.

Juvenile Idiopathic Arthritis (JIA)

The term commonly used to describe chronic arthritis in childhood. JIA generally has a much better outcome and is very different from adult rheumatoid arthritis.

Leg-Length Discrepancy

A difference in the length of the two legs that may be caused when arthritis affects one knee more than the other, causing the more affected leg to grow faster.

Morning Stiffness

Joint stiffness occurring after the joint has been kept immobile overnight. The duration of the morning stiffness is one indication of how much inflammation the child has in the joints.

Oligoarticular Juvenile Idiopathic Arthritis

A form of JIA in which four or fewer joints are affected.

Polyarticular Juvenile Idiopathic Arthritis

A form of JA in which five or more joints are affected.

Prognosis

The best estimate of the course of a disease and how its progress may affect a child's growth and development.

Psoriatic Arthritis

A form of JIA in which arthritis occurs in association with psoriasis (scaly red rash). The arthritis may start before the skin rash.

Remission

A term used to describe the times when the arthritis seems to have disappeared. The first remission may be permanent and the child may never have arthritis again.

Synovium

The inner lining of the joint, which produces synovial fluid, which bathes and nourishes the cartilage. In Juvenile Idiopathic Arthritis, it is actually the synovium, which is inflamed. This is called "synovitis".

Systemic Juvenile Idiopathic Arthritis

The form of juvenile idiopathic arthritis, which also produces high fevers, a rash, swollen glands, enlarged liver and spleen and may involve inflammation of the lining of the heart or lungs.

Tendon

A band of tough, rope-like tissue, which attaches muscle to bone so that the muscles can move the joint.

Uveitis

(also known as iritis or iridocyclitis)
Inflammation inside the eye(s) that can cause damage to the iris without any pain or evident redness.

II. MEMBERS OF THE HEALTH-CARE TEAM

Dietician

A member of the health-care team who specializes in the evaluation of nutrition, and ensuring an appropriate dietary program best suited to the individual child's needs.

Occupational Therapist (OT)

A specialist who will help your child adjust to the demands of living, school and play. An OT can show your child how to perform ordinary tasks and activities with ease of movement and minimal pain and discomfort. When necessary, an OT can also provide your child with devices (such as modified pencils and eating utensils) to make things easier.

Ophthalmologist

A medical doctor with specialized training in the examination, diagnosis and treatment of eye diseases.

Optometrist

A university/college graduate who goes on to have special training in performing eye examinations, prescribing glasses and fitting contact lenses. They are not physicians (i.e. not medical doctors) and do not perform surgery. In some areas they may be allowed to prescribe medications. [We recommend that treatment for uveitis and related eye problems, once diagnosed, be done under the care of an ophthalmologist]

Orthodontist

A dentist who specializes in preventing and treating problems with the development of the teeth and jaw.

Orthopedic surgeon

A medical doctor with specialized training in the examination, diagnosis and treatment of bone and joint disorders, with special expertise in the surgical treatment of these disorders.

Pediatrician

A medical doctor with specialized training in the examination, diagnosis and treatment of disorders of childhood and adolescence.

Pediatric Rheumatologist

A medical doctor with specialized training in the examination, diagnosis and treatment of disorders of childhood and adolescence, as well as the examination, diagnosis and treatment of bone and joint disorders in childhood and adolescence, with special expertise in diseases of inflammation.

Physiotherapist

A specialist in physical therapy and splinting who will help design the exercise program for your child. The physiotherapist will also monitor the movement in individual joints as well as the strength of the muscles around the joints. The physiotherapist will continually modify the exercise program to meet your child's needs.

Psychologist

A member of the health care team with specialized training in the diagnosis and evaluation of emotions, and the role that emotions play in people with chronic illness.

Rheumatologist

A medical doctor with specialized training in the examination, diagnosis and treatment of bone and joint disorders, with special expertise in diseases of inflammation.

Social Worker

A member of the health care team who specializes in helping you and your family adjust to a chronic illness. Social Workers also have particular expertise regarding community resources (e.g. educational, transportation, financial) that can benefit you and your family.

III. COMMON LABORATORY AND DIAGNOSTIC TESTS

ANA (antinuclear antibody)

A protein detected by a blood test that is useful for identifying children who are at a risk of developing uveitis (inflammation of the eye)

Arthroscopy

A procedure done while the patient is under general (or occasionally local) anesthetic. A small tube is inserted into the joint, allowing the surgeon to actually look inside and take a

small snip of synovium (a procedure called a "biopsy"). Arthroscopy is sometimes needed to help diagnose the cause of the child's arthritis.

ESR

(erythrocyte sedimentation rate)
A blood test that often is a measure of the total inflammation in the body.

HLA B27

A genetic marker that may be helpful in diagnosing enthesitis-related-arthritis.

MRI

A type of "X-Ray" (but without radiation) that examines joints and surrounding structures using magnetic fields. Excellent pictures of the inside of the joint are obtained. The test takes about one hour, and the child has to lie still. Sometimes, the doctors and nurses in the MRI unit will have to give your child a mild sedative to allow them to lie still for the test.

Rheumatoid Factor

A blood test which is positive in adults with rheumatoid arthritis and in a very few older children who have polyarticular JIA.

IV. COMMONLY USED TREATMENTS AND MEDICATIONS

Anti-Inflammatory

A medication that helps to reduce inflammation in the joints.

Insoles

Devises placed in shoes to keep the foot in a position of improved function.

Lift

A raise put in or on the shoe worn on the shorter leg so that the legs are of equal length when walking.

Orthotics

A term that includes devices that keep bones and joints in good positions (e.g. splints, insoles).

Splints

Devices made of special plastic designed to help hold joints in the proper position during day or night activities.

Slit-Lamp Examination

A special eye exam given by an ophthalmologist to check for uveitis. The exam is painless and simply requires having the patient put their chin on the chin rest of a machine that shines a special light into the eye.

V. OTHER DISORDERS TREATED IN A PEDIATRIC RHEUMATOLOGY CLINIC

Dermatomyositis

A disorder with inflammation of the muscles and skin that results in muscle weakness.

Fibromyalgia

A painful disorder defined as generalized aching in many areas of the body, with specific tender spots that hurt when pressure is applied.

Growing Pains

A disorder in which young children awake during the night complaining of severe calf, shin and thigh pains. There is no relation to growth. Arthritis does not occur together with growing pains.

Lyme Disease

A disease caused by a bacterium transmitted by a tick bite. The arthritis of Lyme disease is usually mild and of a short duration.

Reactive Arthritis

A form of arthritis that occurs one to several weeks after an infection somewhere in the body other than in the joints. This form of arthritis is usually of short-duration.

Rheumatic Fever

An inflammation of the joints and heart that is a complication from an infection with the bacteria streptococcus (or "strep") that infects the throat.

Systemic Lupus Erythematosus (SLE, or Lupus)

A chronic, rheumatic disease, which causes inflammation of the body's tissue and can affect any organ of the body. Arthritis is common in SLE.



The Arthritis Society provides education, support and solutions to people living with arthritis, giving hope for a better life – today and tomorrow.

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