



SPREAD THE WORD

International **WORD-Day** “**World Young Rheumatic Diseases Day**” is an annual event that will take place for the 2nd time, on March 18th 2020.

The objectives of this day are to raise awareness to rheumatic conditions in children and young people, by giving parents and doctors tools to recognize symptoms which require attention. Raising awareness of pediatric rheumatic diseases will help to aid the process of diagnosis, especially of rarer diseases.

It is up to us, parents, teachers and healthcare professionals to make sure that they get optimal care as early as possible to ensure that they have the best chance of leading a healthy life, with minimum pain.

Events taking place around
the world

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WORDDAY2020

MAGAZINE

Children get rheumatic diseases too

Early diagnosis changes lives

WHAT IS WORD DAY?

Pediatric or juvenile rheumatic diseases are often unknown, not only to the general public, but even to some health care providers. This causes a delay before a correct diagnosis is made.

Early diagnosis and treatment are so important that the European Society for Pediatric Rheumatologists (PReS) and the European Network for Children with Arthritis (ENCA) are jointly inaugurating **World Young Rheumatic Disease Day** or **WORD DAY** for short.

On March 18th, pediatric rheumatologists, patients and parent associations across the globe will reach out to **SPREAD THE WORD** that children and young people get rheumatic diseases too.



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WHAT CAN BE DONE TO HELP CHILDREN WITH RHEUMATIC DISEASES?

First and foremost—awareness. If your child exhibits swollen joints, muscle weakness, rash, recurring fever that peaks in the evening, or complains of sore fingers or stiff joints, especially in the morning or after rest, don't assume that he is acting up. Make certain that he sees his doctor, and if necessary is referred to a pediatric rheumatologist.

Secondly, if your child is already diagnosed with a rheumatological disorder, take full advantage of the excellent medical opportunities your child has to maintain his health.

Make sure that your child takes his medicine on time and visit your child's physiotherapist regularly and keep up with the prescribed exercises.

Exercises will keep your child strong, and make sure that their body has a chance to compensate and recover from the damages of the battle with the illness.

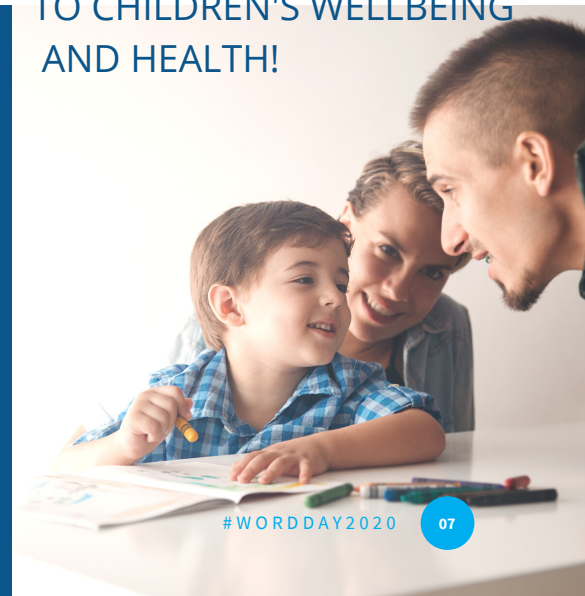
Most importantly, don't forget to take your child to see their doctors regularly—both the ophthalmologist (to rule out the possibility of newly developing uveitis), and the rheumatologist (to make sure the illness is properly managed, and no flare ups are taking place).

Finally, remember that you are not alone. Reach out to parent and patient organizations (<https://www.enca.org/>) to get the support you need for living with a pediatric rheumatic disease, since the diagnosis not only affects the child, but the entire family.

PARENTS ARE KEY TO CHILDREN'S WELLBEING AND HEALTH!

If you are a teacher with a student who has a pediatric rheumatic illness, make sure to speak with the child and their parents, to see if they are managing with their everyday tasks.

They might have difficulty writing or carrying their bag. Many children with pediatric rheumatic diseases find that sitting still for a whole lesson leaves their joints stiff and sore, and they need to get up to stretch during class.



NEW MEDICAL OPPORTUNITIES FOR CHILDREN

The last 25 years have opened many new treatment options for people with rheumatic diseases.

Previously, medicine had little to offer children, and many spent their childhood in pain, often with the prospect of lifelong disability. A young woman who's lived with rheumatic disease from childhood reflected on the damage that has been caused to her arm and finger joints. She said that if she had to be sick, she wishes it would have been now, when medicine could actually help her and keep her joints fully mobile.

Today, due to pediatric-focused medical research and the advent of biologic medicines, tested specifically with children, the majority of children who receive medical and other supportive treatment can achieve remission, whereby their condition is managed well, with little or no permanent damage. Since damage to joints, muscles and tendons is cumulative, early diagnosis is crucial. Early detection usually provides a better prognosis, while delay, misdiagnosis and subsequent mistreatment can worsen the damage that the conditions can cause.

WHAT ARE PEDIATRIC RHEUMATIC DISEASES?

Pediatric rheumatic diseases are a group of long term chronic inflammatory conditions of the musculoskeletal system.

These illnesses range from the relatively common to the extremely rare, including: Juvenile Idiopathic Arthritis (JIA); Juvenile Systemic Lupus Erythematosus (JSLE); juvenile Dermatomyositis (JDM); Pediatric Vasculitis; autoinflammatory disorders such as Familial Mediterranean Fever (FMF); Rheumatic fever, Kawasaki disease and more.

Many of these conditions are chronic, which means that they persist for many years or indefinitely and need to be managed to minimize their effect on the children's quality of life.

The most common pediatric rheumatic disease is JIA which affects approximately 1 in 1,000 children and has several subtypes.

Rheumatic diseases affect children in many ways. Some widespread conditions, such as SLE and the systemic subtype of JIA, can severely impair children's overall health and wellbeing. SLE, for example, can cause damage to internal organs e.g. kidneys, the heart and the nervous system. Other conditions tend to be more localized and primarily affect the joints or skin, causing pain and restricted joint movement, hampering daily activities and physical development.



www.printo.it/pediatric-rheumatology

TSIPI'S STORY

A MOTHER TALKS ABOUT HER SON'S JOURNEY WITH JIA

It was the morning of our son's 10th birthday. Our preparations were cut short when cries of distress from our youngest child David —then almost two— brought me to his bed.

Something was clearly wrong. I lifted him from his bed and tried standing him up, only to see him crumple up in pain on the floor.

Always busy and on the go, running from the age of 10 months, this morning he seemed unable to stand, never mind run or walk. What could possibly be wrong? We quickly undressed him and saw: both his knees had swelled to the size of tennis balls.

Our 10 year old had to celebrate his birthday without us, and we headed to the hospital.

Later that day in the hospital, all the tests were clear, and over the next few weeks his knees improved and went back to normal – until the next flare up.

Knees, ankles, neck, fingers, jaw—any joint could suddenly become inflamed, sore and painful. Because his flare-ups were so sporadic, it took a while to receive a final diagnosis: David has JIA, Juvenile Idiopathic Arthritis.





HOW ARE PEDIATRIC RHEUMATIC DISEASES DIAGNOSED?

Since they are relatively uncommon, pediatric rheumatic diseases are often difficult to diagnose and are sometimes unknown to health care providers. This can cause a significant delay before a correct diagnosis is made.

Some family physicians (GPs) do not expect children to suffer from conditions that tend to be associated with older people, attributing swelling, pain and other symptoms to unreported injuries, growing pains or psychosomatic pain.

Nobody knows children better than their parents and carers. Healthcare professionals should actively engage and listen to parents and carers during consultations, to jointly work out what is wrong.

SINCE DAMAGE TO JOINTS, MUSCLES AND TENDONS IS CUMULATIVE, EARLY DIAGNOSIS IS CRUCIAL

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A young child went to see an orthopedic doctor with a sore swollen elbow. The doctor placed the child's elbow in a cast, explaining that it must be fractured (though his mother insisted that her young child had not fallen). Weeks later when no improvement was seen, the doctor recast the arm.

Eventually the child was referred to a pediatric rheumatologist, who diagnosed JIA and began administering the correct anti-inflammatory treatment.

It took months to repair the damage done to the elbow by being placed in a cast.

The most important treatment for inflamed joints is movement, to keep the joints from becoming fused, which can cause lifelong damage and disability.

One mother reported how she went from doctor to doctor seeking help for her young daughter who cried in pain and refused to walk, only to be accused by doctors of spoiling her daughter, who, they claimed, had nothing wrong with her and must have simply been seeking attention.



CHILDREN SHOULD BE REFERRED TO PEDIATRIC RHEUMATOLOGISTS TO RECEIVE OPTIMAL CARE

WHO TREATS PEDIATRIC RHEUMATIC DISEASES?

When it comes to pediatric rheumatic diseases, children are not just small adults. The rheumatic which affects them is different from adult rheumatism. It requires different treatment, runs a different course and has different complications. That is why children must be referred to pediatric rheumatologists to receive optimal care.

One of the most severe complications to look out for in children living with JIA is uveitis, an inflammation of the eye which can lead to blindness. This complication tends not to occur in adults.

A pediatric rheumatologist recently recounted the story of a young boy who had been wrongly diagnosed, and subsequently treated with intravenous antibiotics for almost a year to treat his painful swollen joints. By the time he was finally referred to the pediatric rheumatologist, one of his legs was almost immobile from the continued inflammation, and his eyesight in one eye was badly damaged by uveitis. A young man, well beyond his childhood years, remarked to a pediatric rheumatologist after years of suffering: "I suffered all these years without knowing what was wrong, and not knowing that one of the world experts in my condition lived across the road from me!" Luckily, more and more doctors are becoming aware of these conditions.