

## **CONFIDENTIAL**

### **CHILD'S MEDICAL INFORMATION**

The following is important information about my child's medical condition and how the condition may affect their ability to fully participate in a regular school setting. The goal is to try to normalize every day school routines/activities while also meeting my child's unique needs in the least disruptive manner. This document is not intended to replace any existing Individual Educational Plan (IEP) or the 504 Plan, but rather to serve as a supplement or addendum to enhance my child's education. Medical information will be updated at the beginning of each new school year and throughout the school year as deemed necessary.

**"We may not look sick, but turn our bodies inside out and they will tell different stories."** Wade Sutherland

CHILD'S NAME: \_\_\_\_\_

ACADEMIC YEAR: \_\_\_\_\_ GRADE: \_\_\_\_\_ DOB: \_\_\_\_\_ AGE: \_\_\_\_\_

HOME ADDRESS: \_\_\_\_\_

PARENT/LEGAL GUARDIAN: \_\_\_\_\_

PARENT/LEGAL GUARDIAN CONTACT NUMBER: \_\_\_\_\_

SCHOOL: \_\_\_\_\_

#### **EMERGENCY CONTACT (2 PEOPLE)**

NAME: \_\_\_\_\_

RELATIONSHIP: \_\_\_\_\_ PHONE NUMBER: \_\_\_\_\_

NAME: \_\_\_\_\_

RELATIONSHIP: \_\_\_\_\_ PHONE NUMBER: \_\_\_\_\_

## Overview of Juvenile Spondyloarthritis

“Juvenile Spondyloarthritis (JSpA), is the medical term for a group of childhood rheumatic diseases, which cause arthritis beginning before the age of 16. Juvenile spondyloarthritis includes enthesitis-related arthritis, undifferentiated spondyloarthritis, juvenile ankylosing spondylitis, psoriatic arthritis, reactive arthritis, and arthritis associated with inflammatory bowel disease (also called enteropathic arthritis).”

“JSpA typically causes pain and inflammation in the joints in the lower part of the body, for example, the pelvis, hips, knees and ankles. Other areas of the body can also be affected, such as the spine, eyes, skin, and bowels. Fatigue can also occur.”

“The more common symptoms of juvenile spondyloarthritis include arthritic pain, especially around the heels or toes, around the knee, and in the lower back. Frequently, the first symptom is pain at the site where ligaments and tendons attach to bone (the inflammation at this location is called enthesitis). Other joints may also be affected, particularly the sacroiliac (SI) joints – which are the joints at the base of the spine, where the spine meets the pelvis.”

“Sometimes children with spondyloarthritis develop other symptoms as well. These may include fever, psoriasis (a scaly skin rash), colitis or Crohn’s disease (inflammation of the intestine), and iritis (inflammation of the eye that may appear like pink eye).”

### Disease Course/Prognosis

“JSpA is characterized by periods of disease activity and remission. It is not uncommon for children to have good days and bad days, sometimes these are hard to predict.”

“Although juvenile spondyloarthritis is a chronic disease with no cure, the length and scope of JSpA varies in each patient.”

“It is important to note that disease progression and the severity of symptoms may also vary between people with juvenile spondyloarthritis. Some children may experience a mild, short-term disease, whereas others experience a more severe, long-term condition.”

“It is difficult to predict a long-term outcome for this disease, especially in its early stages. The disease can sometimes last for months or years and then go into periods of remission (when the patient seems cured). It can also persist into adulthood.”

Retrieved on November 14, 2018, from [www.spondylitis.org](http://www.spondylitis.org)

### What Can You Do To Help?

A child who has been diagnosed with Juvenile Spondyloarthritis (JSpA) may experience a limited range of motion due to inflammation and pain in the joints. This in turn, may affect the child’s ability to perform simple everyday movements such as bending, turning, stretching, and twisting. A lack of movement may cause an increase in pain as well as stiffness. Sitting or standing for long periods of time often will increase pain and stiffness. Allowing the child to get up to stretch or stand up in class will help manage pain and stiffness. Some children may experience limitations performing physical activities such as jumping, running, hopping, and kicking. Also, children with JSpA may experience fatigue due to chronic pain, inflammation, and difficulty sleeping.

Flares are quite common in children suffering from JSpA. This is when the disease is most active and symptoms are exasperated. Overexertion and stress can elicit a flare.

For more information about JSpA, please visit the SAA Juvenile Spondyloarthritis website at [www.spondykids.org](http://www.spondykids.org) or the SAA main website at [www.spondylitis.org](http://www.spondylitis.org). Additional information can be found in the Juvenile Spondyloarthritis brochure located on our website.

### MY CHILD’S CURRENT HEALTH STATUS

- My child’s symptoms present at the beginning of the school year:

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- When my child is experiencing a flare and/or pain, symptoms may include:

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- Special accommodations my child may require (If an IEP or 504 Plan is in place, please also refer to the educational plan ):

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- During a flare and/or when receiving steroid treatment, my child may experience a significant increase in appetite. At the beginning of each semester, I will provide the following snacks:

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\*Please note: Although my child may not be experiencing a flare, my child may still experience ongoing fatigue and pain. Pain is emotionally and physically draining. It can affect the child’s ability to concentrate, read, write, and engage with other children.\*

- The following are physical activities my child is unable to engage in:

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- Symptoms that warrant immediate medical attention:

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### MY CHILD’S DOCTOR(S) & MEDICATION(S)

- Primary Physician (Name & Contact Number):

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- Rheumatologist (Name & Contact Number):

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- My child is presently taking the following medications:

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- The following medications will remain at school:

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### ALLERGIES

- My child has the following allergies:

Yes/No	Food	
Yes/No	Animals	
Yes/No	Bees	
Yes/No	Plants	
Yes/No	Medications	
Yes/No	Other	



**Our Mission:** "To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest."

- Symptoms that may indicate an allergic reaction:

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\*PLEASE NOTE: If my child should experience difficulty breathing, swallowing, nausea, vomiting, skin reaction, weak or rapid pulse, and/or dizziness, it may indicate a life threatening allergic reaction, ANAPHYLAXIS. Please call 911.

OTHER ON-GOING MEDICAL ISSUES AS WELL AS DEVELOPMENTAL DELAYS UNRELATED TO  
JUVENILE SPONDYLOARTHRITIS (JSpA)

(ex. Diabetes, Seizures, Lupus, Fibromyalgia, Heart Murmur, Migraines, ADHD, Speech Delay/Impairment, etc. . . )

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## EMOTIONAL, SOCIAL, AND BEHAVIORAL ISSUES

Juvenile Spondyloarthritis (JSpA) affects children in many different ways. The chronic pain and/or inflammation can be physically, mentally, and emotionally taxing. This in turn may affect the child’s ability and/or desire to socialize. Children can also experience poor self-esteem and/or depression if/when unable to perform everyday physical activities that are normal for their peers. Consequently, their ability to perform to their highest academic potential may be impacted, as their focus is on the pain. A child’s behavior is often a reflection of their overall physical, psychological, and emotional wellbeing. Possible behaviors and states of being that may indicate pain and/or discomfort in a child suffering from a chronic, painful disease include: restlessness, agitation, anxiety, fidgeting, appearing inattentive or distracted, and being tearful, emotional, or withdrawn.

“Not antisocial, not snobbish, just exhausted from fighting a chronic disease!” Author Unknown (Agora the platform)

- When my child is in pain and/or experiencing a flare, he/she may exhibit the following behaviors:

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- Sometimes alternative activities may be helpful in reducing the child’s focus on the pain or their inability to perform a certain task. Activities that help my child cope when in pain and/or experiencing a flare:

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## SPEECH & LANGUAGE

Speech is imperative for communicating and expressing pain. Age, limited vocabulary, a speech delay or impairment can affect a child’s ability to communicate. Fear and anxiety about what they are feeling at the moment can also inhibit the child’s ability to describe what they are feeling. Children can describe pain in many ways: sharp, stabbing, dull, burning, achy, sore, tender, stiff, hurt, bad, and pounding.

Visuals are often helpful for children when describing pain and indicating pain level. A pain scale is a useful tool to help a child rate their pain level. This tool is not to replace observing any behavioral or physical signs of pain.

## PAIN MEASUREMENT SCALE

