

# LIVING WITH SJIA

Systemic juvenile idiopathic arthritis (SJIA), also known as Still's disease, is an autoinflammatory condition that causes fevers, rash and joint pain which impact the emotional and financial well-being of SJIA patients and their families.<sup>1</sup>

## DAILY IMPACT ON LIFE

The **physical** and **mental quality of life** of SJIA patients is **lower** than other children. Patients' **general health** perceptions, **physical functioning**, and parents' **emotional impact** are most impaired\*

### ASSISTANCE REQUIREMENTS

**54%**

of patients require an assistive device<sup>1</sup>



### SCHOOLING IMPACT

SJIA patients miss

**10%**

of schooling per year due to SJIA<sup>1</sup>

*"[SJIA] has completely consumed our lives at this point. I feel as if I walk around in a fog. My daughter is normally a very active child [...] Plays lots of sports, and now doesn't want to do anything. My husband and I are heart broken [...] We have lots of questions and concerns..."*  
Parent of child with SJIA<sup>2</sup>

## PATIENTS

*"I was so concerned at what the future would hold for him. I was confused at why it was happening to him, I was angry, I was worried [...] I went through so many emotions, and often still do..."*  
Parent of child with SJIA<sup>2</sup>

## EMOTIONAL IMPACT

**45%** of parents are frequently very stressed about the long-term impact of SJIA<sup>1,#</sup>

### DISRUPTION TO WORK

**36%**

of caregivers have reduced their hours or stopped working<sup>1</sup>



### SOURCES OF STRESS

**27%**

of parents are frequently very stressed about their child's ability to become an independent adult<sup>1,#</sup>

## FAMILIES

1. Sheno S., et al., Poster presented at the 2016 ACR/ARHP Annual Meeting, Number 2376-2. 2. Modica RF., et al. *Rheumatol.* 2016; 8: 61-71

\*Compared to normative values using the Child Health Questionnaire-Parent Form 50 (CHQ-PF50); #Caregivers are reported who answered this was a source of stress "4 - Often" or "5 - Very often" and "4 - Very much" or "5 - Extremely" stressful.