



SETTING CHILDREN WITH JSpA UP FOR ACADEMIC SUCCESS

by Mary Ann Poladian

The approach of fall brings a new school year and excitement for the future. Yet it can also bring challenges for families affected by spondyloarthritis (SpA). I remember feeling overwhelmed, wondering how I could best support my daughter as she started high school. An intimidating thought dawned on me: I didn't know what I didn't know. We had been so busy with our daughter's medical concerns that we hadn't focused on how to find support for her in an academic setting. Terms like "academic accommodations," "IEPs," and "504 Plans" were unfamiliar. However, that would soon change.

Navigating school regulations and getting your child proper support can be hard for parents. That's why I am sharing the details of our journey with my daughter through high school and beyond, and the resources available to all students living with juvenile spondyloarthritis (JSpA)—from my perspective as both a mother and a professional college counselor.

My daughter was diagnosed with JSpA in eighth grade, after searching for nearly two years for the cause of her continued back pain and Achilles tendinitis. As she entered high school and her rheumatologist finally got her symptoms under control, we could then concentrate on her needs in the context of school. We spent weeks compiling a patchwork of information. We educated ourselves on academic accommodations and the laws protecting children from discrimination and ensuring access to educational and related services in public K-12 schools. These include: The Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and Title II of the Americans with Disabilities Act (ADA), as well as the Family Educational Rights and Privacy Act (FERPA), which gives parents and guardians certain rights regarding their children's education records.

Based on what we learned from our research, at my daughter's next rheumatology visit we requested a letter documenting her diagnosis, summarizing the functional limitations she experienced in her daily life, and outlining the appropriate accommodations that would attempt to level the playing field for her in the school setting. We contacted her high school to set up an evaluation for a 504 Plan, which is a formal plan schools develop to help support children with disabilities. We provided the documentation to the school in advance of our appointment. During our meeting with school administrators, we discussed the Section 504 Plan details, and the accommodations she was approved to receive in school were noted. We requested a meeting each year of high school to update the 504 Plan to meet her needs.

There are several concrete and proactive steps you can take to secure needed accommodations for a student. Online resources are available where you can research accommodations, including on SAA's website for kids with JSpA and their families, **spondykids.org**. You can also download and customize SAA's JSpA Medical Information Form to prepare for your visit with your child's school. If your student will be undergoing standardized testing in preparation for college, you can find more information on applying for accommodations for the SAT and AP exams under Services for Students with Disabilities at **CollegeBoard.org**, and for the ACT under the ACT Policy for Requesting Accommodations for the ACT Test at **ACT.org**.

As your teen researches and prepares to apply for college, it's important to understand that colleges and universities provide services and support to students under different laws than those that govern services in the K-12 system. You will find information about how to navigate receiving accommodations in college through different resources than those for grade school and high school.

Students do not need to disclose their diagnosis or disability in their college applications. However, a student's resilience in dealing with the impact of an illness can be a central part of their story in their college application. Colleges and universities in the U.S. cannot discriminate against people with disabilities and must provide certain accommodations. Additionally, FERPA rights transfer to the student when they reach the age of 18 or attend school beyond the high school level. When students are in college, parents do not have rights under Section 504 or ADA to speak for their student, unless the student signs a waiver, which allows the college to release specific information to parents.

One place to start learning more about the transition to college for students in need of accommodations is the U.S. Department of Education website. In addition, each college typically has its own disability services webpage. Two college webpages I recommend are **disabilitysupport.gwu.edu/document-your-disability** and **academics.lmu.edu/dss**. Some of the most common types of accommodations include test-taking accommodations, such as extended time and alternative formats, note-takers or scribes, and course substitutions and/or waivers.

One crucial difference between high school and college is that college students may be financially responsible for personal accommodation needs such as individually prescribed devices, readers for personal use or study, or other services. Students may be eligible for financial assistance from the Department of Rehabilitation in their state, and students with JSpA may apply for specific scholarships, including the AbbVie Immunology Scholarship and Arthritis Champions Scholarship.

In choosing a college, students and their families should consider several factors. These include access to rheumatology care, whether there are lots of stairs on campus or in residential halls, access to medication delivery, and options for the storage of medication if it requires refrigeration (and whether the campus

has infusion facilities if needed). Does the campus layout allow students to easily walk to classes, get to the dining halls, and access appropriate housing to meet their needs? A visit to the campus is strongly suggested before a student decides to attend.

Once a student has chosen the college they will be attending, applying for disability services in a post-high school setting is typically a four-step process:

1. Register on campus as a student with a disability
2. Provide proof of your disability
3. Meet with a disability services office representative for an intake interview
4. Receive an approved accommodations letter and notify professors of your eligibility for accommodations

This process can differ slightly depending on the college, so be sure to be proactive and research what is needed in advance.

College disability offices follow the Association for Higher Education for Disability (AHEAD) guidelines. However, colleges are under no obligation to continue the specific services given in high school or to adhere to the recommendations of an outside physician. The college reserves the right to determine what services and support to offer based on the documentation of disability, their interview with the student, and their internal policies.

Throughout this process, students with JSpA must learn to advocate for themselves and become responsible for their own academic success moving forward. As for my daughter, she learned to navigate this process and become her own advocate. She attended Princeton University and Wake Forest University School of Medicine and is currently a resident physician.



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