

Living with APDS: Resources to help you advocate for yourself or your family at school



Not an actual patient

The healthcare needs of someone living with a primary immunodeficiency (PI) like APDS can be complex. There are a number of legal protections in the US that may help support your child at school.

Developing a 504 plan*

- To be protected under Section 504 of the Rehabilitation Act, it is necessary to prove that the student has a physical or mental impairment that substantially limits one or more major life activities. A student does not need to receive special education services to be eligible.
- Send a written request to the school to schedule a meeting with the school's 504 coordinator or counselor, teachers, and other relevant staff to discuss your child's needs and develop the plan.
- Collect medical records, reports from healthcare providers, and any other relevant documentation that supports your child's need for accommodations.
- Work with the school to identify specific accommodations and supports your child requires. This may include modifications to the learning environment, health-related accommodations, or other supports. Make sure that requests are specific and detailed.
- The 504 Plan should be personalized to your child's specific needs and reviewed regularly.

Developing an Individualized Education Plans (IEPs)*

- An IEP is a written document for students ages 3-21 that provides special education services and support tailored to their unique needs.
- Children whose PI affects their ability to learn may qualify for an IEP under the Individuals with Disabilities Education Act (IDEA).
- You can request an evaluation from the school to determine eligibility for an IEP.
- Gather relevant documentation, such as medical records, psychological evaluations, educational assessments, and reports from healthcare providers.
- Schedule an IEP meeting with the school's special education team, including teachers, specialists, and administrators.
- The plan should outline your child's current level of performance, specific educational goals, accommodations, modifications, and the services your child will receive.
- An IEP can follow a student throughout their school career.

*Applies to all schools that receive federal funding

For older students, plans for transitioning to post-secondary education, employment, or independent living are an important part of the Individualized Education Plan (IEP) and should start by age 14–16.

Helpful Resources

U.S. Department of Education - Office for Civil Rights (OCR) <https://www.ed.gov/>

IDEA (Individuals with Disabilities Education Act) <https://sites.ed.gov/idea/>

The PACER Center offers resources on special education and disability advocacy: <https://www.pacer.org/>

Understood.org offers detailed information on the IEP process <https://www.understood.org/>

NCLD offers resources and guidance on developing IEPs: <https://www.ncl.org/>

IDF School Guide for Students with Primary Immunodeficiency <https://primaryimmune.org/resources/>

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Living with APDS: Resources to help you advocate for yourself at work



Not an actual patient

Legal Protections at Work

Living with a chronic illness may present challenges when trying to seek employment, but there are opportunities to work in an area you are passionate about.

Most people living with PI do not consider themselves as having a disability. However, legal protections in employment under laws such as the Americans with Disabilities Act (ADA) may apply.

- The ADA defines a disability as a physical or mental impairment that substantially limits one or more major life activities.

Americans with Disabilities Act (ADA)

The ADA requires covered employers to provide reasonable accommodations to qualified employees with disabilities. These accommodations are adjustments or modifications that enable individuals with disabilities to perform the essential functions of their job.

- Covered employers are required to engage in an interactive process with the qualified employee to identify and implement appropriate accommodations.

Family and Medical Leave Act (FMLA)

The FMLA is a U.S. federal law that provides eligible employees with unpaid, job-protected leave for specific family and medical reasons.

- Eligibility criteria apply and can be found at the Department of Labor.
- Eligible employees can take up to 12 weeks of unpaid leave in a 12-month period to care for a spouse, child, or parent with a serious health condition. Or for their own health condition.
- Subject to certain exceptions, employees are entitled to return to the same or an equivalent job at the end of their FMLA leave.

Patient Advocacy Organizations

Patient advocacy organizations offer a wealth of information about PI, which can be invaluable in helping to increase understanding of the condition, its symptoms, and its impact on daily life at work. This can help foster a more supportive and informed environment.



Support, advocacy,
and education.

www.primaryimmune.org



Research, education,
and patient support.

info4pi.org



Advocacy and resources for
rare diseases.

www.rarediseases.org



Information, resources
and connections.

globalgenes.org

For more information, visit the websites below:

- U.S. Equal Employment Opportunity Commission (EEOC) - Enforces ADA protections. www.eeoc.gov
- Department of Labor (DOL) - Provides information on FMLA. www.dol.gov
- Guide to Disability Rights Laws <https://www.ada.gov/resources/disability-rights-guide/>



Scan the QR code to access useful resources at the AllaboutAPDS website, including an APDS Emergency Card