



Healthcare and Your Child with Restless Legs Syndrome

A Guide to Partnering with Your Child's Healthcare Team

If your child or teenager is diagnosed with restless legs syndrome (RLS, also known as Willis-Ekbom disease), you will find yourself working with physicians and their staff, school nurses, teachers and insurance representatives.

There will be times when these relationships are positive and will enhance your ability to improve the understanding of RLS and quality of care for your child. But, there may be other times when relationships are challenging.

This handout provides information to help you and your family act as equal partners with your child's healthcare team.

Choosing Healthcare Professionals

Look for individuals who listen well and explain things clearly and completely. You will want a doctor or nurse with whom both you and your child feel comfortable. Does the doctor only talk to you as the parent and ignore your child (the patient)? Find someone who communicates easily and equally with you both.

Look for a team player. This is a healthcare professional who shares your child's medical information with you and others who need it, such as other doctors, teachers and school personnel.

If, after trying to build a good relationship with your child's healthcare provider, you feel that you do not understand or respect each other, you may want to think about making a change. This can be challenging because there are not many providers who are comfortable treating and following children with RLS over time. But it is not impossible and may be worth the effort for your child and family. Be careful not to burn your bridges, as you may need to visit this provider again in the future. Acknowledge and thank the provider for his or her time and effort in working with your family.

Asking Questions

Every question that you ask is important:

- *Ask for clarification* from any healthcare professional (doctor, nurse practitioner or nurse) when you don't understand a term they use.
- *Ask for more information* when you don't understand why a treatment or test is recommended.
- *Ask about side effects* and whether testing (clinical trials) has been conducted on children for this treatment.
- *Ask if written materials are available* to read more about the suggested treatment or test. These materials will help you provide accurate answers to your child's questions following the doctor visit.
- *Ask about testing for iron deficiency* (serum ferritin). This is important because iron deficiency is very often associated with RLS in children. If your doctor prescribes iron drops or tablets, ask about possible side effects like constipation, and what can be done to prevent them.
- *Ask about attention deficit hyperactivity disorder* (ADHD) if you suspect your child may have it, in addition to RLS.
- *Keep asking questions until you are satisfied* that you and your child understand everything you need to know.
- *Finally, ask if there is anything you haven't thought of* regarding care for your child.

Keeping Good Records

You are the one constant in your child's changing healthcare landscape. Since you will see many different professionals over time, it is important to keep track of important information. Good records make good sense. You can do it online, in a three-ring binder, or however is convenient for you. Up-to-date information is especially important if your family relocates to a new community or area. The following are suggested records to keep:

Health information

- Dates of diagnostic tests such as sleep evaluations
- All laboratory reports including ferritin levels
- Allergies to drugs, foods and other substances
- Immunization records
- Any unusual reactions to treatments or substances (may help identify RLS triggers)
- Family history of RLS
- RLS treatment plans
- Personal Health Summary provided by your child's physician following an appointment
- List of current medications (including prescription drugs, over-the-counter medications, and supplements)

Health insurance

- Names, addresses and phone numbers of insurance providers or state financial programs
- Copies of insurance policies
- Notes on how the insurance company or state program has responded to your claims
- Your child's social security number
- Copies of any appeals that you have made to your insurance company or state program
- Receipts for copayments, deductibles or other out-of-pocket costs that you have paid

Education

- Copies of all Individualized Education Plans (IEP) or 504 accommodations
- Names, titles and telephone numbers of school personnel
- Education evaluation reports (achievement reports)
- Copies of all written correspondence with school staff
- Notes and dates from meetings with school staff

Navigating Your Child's Insurance or Public Program

Whether your child has private medical insurance or participates in a public program, you will need to navigate tasks like enrolling your child in a plan and seeking reimbursement for medical services. It is important to ask questions so that you fully understand all terms and requirements, and to document your phone calls and correspondence for reference in the event you need to appeal a future claim or decision.

Questions to ask about your child's insurance or public program

- What program choices are available to us?
- How do I apply?
- What information do I need for the application process?
- Is there an applicable copayment or deductible?
- How long will it take before coverage begins?
- Is there an annual renewal process?
- Are there any circumstances that might change our eligibility?
- What are the complaint and appeal procedures?
- Is this a self-insured health plan?

Questions to ask about available services under your child's insurance or public program

- What services will be covered?
- What services will not be covered?
- Do I need prior approval from the plan to see a specialist? If so, what is the process to get that approval?
- Is there a list of doctors, specialists, pharmacies and hospitals available under this plan?
- Are pediatric specialists available under this plan?
- Are there any annual/lifetime limits or caps for services under this plan?

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The RLS Foundation is dedicated to improving the lives of the men, women and children who live with this often devastating disease. Our mission is to increase awareness, improve treatments and, through research, find a cure for restless legs syndrome.

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