

Equipment

Choosing Equipment

The initial evaluation is very important in determining what kind of equipment to choose. It should be done by your child's local physician, physical or occupational therapist, or a local medical center, who may consult with vendors (equipment supply stores) to find the right piece of equipment for your daughter.

It is good to do your own research. Call or compose a form letter requesting catalogs from a variety of rehabilitation equipment vendors. Browsing through the catalogs will educate you as you comparison shop for styles, features, models, colors and prices, all in the comfort of your own home. Some vendors will bring the equipment to your home or will allow you to keep it on a short trial basis. It is helpful to talk to other families of girls with RS syndrome and ask how they feel about their daughters' equipment. Just remember that the piece of equipment should be suited to her individual needs. When you meet with the equipment representative, ask questions about items that otherwise might not have been explained. Vendors often have their favorite pieces of equipment and companies with whom they deal. Once you are an informed consumer, you will be an active participant in the evaluation process.

Funding Equipment

Contact your insurance company and check out your policy thoroughly. Follow any required procedures to the letter. Any deviation could result in a reduction of benefits. You may need pre-approval. If so, take care of it right away. After you purchase the equipment, it may be too late. If you need a prescription for the equipment, get the forms you need from the insurance company and take them to your physician to complete. After an evaluation, the physician will write a prescription describing the equipment which is recommended, along with a letter of justification. Here is what to include in the letter of justification:

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Name, age, sex and diagnosis of RS. Include a brief and simply worded explanation of the diagnosis with symptoms and prognosis. For example: Susie Q., 6 years, female with Rett syndrome – a neurological disorder which leads to loss of speech, gross and fine motor skills and muscle weakness, seizures and breathing irregularities.

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Add a description of her functional skills. For example, Susie is non-ambulatory, nonverbal, incontinent and dependent for feeding, bathing, and dressing.

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Describe the durable equipment she already has and explain why the new equipment is needed.

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Describe the piece of equipment which is being prescribed now and why it has been requested. For example:

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"Susie needs a light weight manual wheelchair because she can't walk. She must have a properly supported seating system to prevent scoliosis and avoid pressure sores."

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"Susie needs a stroller because she can't walk long distances. She tires easily over long distances and runs greater risks of falling. She does not have purposeful hand use and cannot self-propel a wheelchair. She does not need the complex positioning support system of a wheelchair at this time."

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"Susie needs a toilet chair because she can't sit independently on the toilet. She cannot be toilet trained without appropriate equipment for her to be successful. Toilet training reduces long term damage to her skin and relieves the cost of diapers."

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"Susie needs a bath chair because she can't sit or stand independently for bathing or showering. She has an increased risk of serious injury if an accident occurs while bathing without appropriate equipment."

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Include the name and phone number of someone the funding agency can call if they have questions. Signatures should include the person writing the letter and the prescribing physician if possible.

Here is the process of insurance funding: The vendor (equipment supply company) provides a quotation of cost. The vendor sends it along with the doctor's prescription and letter of justification to the funding agency or insurance company. Insurance and governmental agencies generally pay the vendor directly. If a family chooses to deal directly with the funding source, it becomes their responsibility to work closely and communicate with the vendor regarding funding approvals or denials.

You should start early, especially for large or custom items. It may take 4 to 6 months to get a new wheelchair. If your request is denied, follow up with an appeal. You may have to make some phone calls and get more documentation. You may have to get a second medical opinion, but the extra work often pays off.

Other Funding Sources

There are a number of funding sources for devices and services and it is important to go through them in proper order. First, try insurance or Medicaid, schools or the Vocational Rehabilitation Agency. Each source has its own procedures and policies. Do your homework first; check to find out what has worked for others.

Insurance/Medicaid: A claim of medical necessity is a must. Denial is not the end of the story. Make it clear you will appeal.

Schools: Schools may purchase communication devices to enable the student to participate in a normal academic setting. However, the device belongs to the school, not the student.

Vocational Rehabilitation Programs: Vocational Rehabilitation Programs may fund equipment if the lack of it is the main obstacle to employment. Eligibility requirements vary from state to state. Look in the white pages of your local telephone book.

Private Corporations: Businesses can take a tax write–off for a charitable contribution and will get good public relations benefits at the same time.

Trust Funds: Check with trust division of banks in your area to see if a trust fund exists for the purpose of helping people with disabilities. Banks don’t often advertise this availability.

Service Clubs: Local civic organizations such as the Lions Clubs, Kiwanis and Rotary often contribute to the purchase of equipment.

Fundraisers: Churches and other organizations are often helpful in putting on a fundraiser in your community, such as a car wash, bake sale, dinner or raffle.

Wishmakers: These organizations grant wishes to people with specific needs. Contact the Sunshine Foundation at 4010 Lefick Street, Philadelphia, PA 19135 or call the Make a Wish Foundation at 1–800–722–9474.

Public Appeals: Contact local media to help get the word out in the community.

Equipment Recommendations from our Families:

Arm Braces by a Rett grandmother "...bright, colorful arm braces...a source of positive attention...armbraces.com. In addition to armbraces, we offer bibs, rain ponchos, winter ponchos, neckerchiefs, Hatchback shoes, and AFO socks."

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