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General Recommendations for girls with Rett Syndrome:

1. Orthopedics: It is important that the girls be followed periodically (at least annually) by an orthopedist, preferably a pediatric orthopedist. Girls with Rett syndrome are typically hypotonic early on and then develop increased muscle tone. It is important that this muscle tone be followed closely so that the secondary effects such as muscle contracture (including scoliosis) and joint deformity can be minimized through the use of bracing, orthotics and other tone management options. A pediatric orthopedist can help with this and help in the decision making process as to which intervention will be the most appropriate and useful for each child and her family.

2. AFOs: AFOs can improve stability in standing and during gait in the presence of either hypotonicity or hypertonicity. Hypotonicity interferes with the ability to maintain standing because of instability at the foot and ankle caused by collapse of these structures under body weight. Hypertonicity forces her into plantarflexion and knee extension, which interferes with her abilities to access balance reactions and access knee flexion. Many of the girls that walk demonstrate dynamically increased plantarflexor tone during standing activities and gait which interferes with abilities to access balance reactions. AFOs can help minimize the negative effects on balance of excessive, unexpected plantarflexion. Many of the girls demonstrate alternately hypotonic and hypertonic plantarflexors in standing, which makes them much less stable without the external assistance of AFOs.

3. Apraxia: Girls with Rett syndrome typically develop gross motor apraxia, or the inability to motor plan an activity, at some point. You can read more about this in the Rett syndrome handbook. Generally speaking, if she begins to have difficulty doing things she was previously able to do, it is important to find the least amount of help she needs in order to get started with, or finish, the activity. This is something that a physical therapist can help you determine. For instance, she may just need a little more “reaction or processing” time; or to have the directions verbally repeated; or she may need a demonstration; or she may need you to present a hand, as if to help her up; or she may need some minimal physical assistance to begin the movement; and this will help her internally to get started with the activity.

4. Learning new skills and maintaining present skills: Girls with Rett syndrome learn new gross motor activities and maintain previously gained skills through repetition of that activity. For these reasons it is important that each of the girls be expected and made to do as much for herself as she is able. This is why it is important, if she develops apraxia as discussed above, to find the minimum intervention needed for her to complete the rest of the task on her own. Maintaining gross motor skills in girls with Rett syndrome is an “uphill battle” because the tendency in Rett Syndrome is to lose skills due to the development of apraxia over time. It is imperative that they continue to do as much for themselves as they are able because this continuous physical activity is what allows them to maintain their highest level of functional mobility for the longest period of time.

5. School Environment: Given the two discussions above regarding apraxia and acquisition/maintenance of skills, it is also very important that the staff working with a child with Rett Syndrome be very familiar with her abilities and needs. Frequently the girls do better when they have consistent staff with them throughout their day at school and this can not always be achieved without the use of a 1:1 aide. Because it is often difficult for teachers or teaching assistants to give the girls as much attention as they need to be successful in an academic environment, it is often beneficial to everyone involved if a 1:1 is added. The school physical therapist can then train the 1:1 aide in all of the child’s specific physical needs, as he or she will be the person spending the most time with the child and can best carry out the activities discussed in #3 and #4.

6. Other activities: It is generally recommended that families get the girls involved in activities such as swimming and horseback riding if they are not already doing that. These activities are a nice way to keep the girls used to having movement imposed on them, which can provoke anxiety as they get older. It is especially nice if these activities can be done with the whole family as well. If you are unsure as to what is available to you or how to contact them, check with your child’s therapists (PT, OT, Speech) as they may know or be able to get you headed in the right direction in your area.