

SCHOOL

WHICH SPORTS ARE SAFE FOR CHILDREN BORN WITH DWARFISM?

One of the most common questions we hear from parents of short statured children is, "For school physical education and for recreation, what sports are safe for my child to participate in?" This is a difficult question because even the physicians who specialize in dwarfism are not in total agreement on this subject. The answer also depends on the specific type of dwarfism and the severity of orthopedic and neurological complications a particular child may have. Even within the same type of dwarfism, the amount of trauma the spine and joints can take will vary by the child.

Dr. Charles Scott, Chairperson of LPA's Medical Advisory Board, informs me that the medical specialists on that board have agreed to put together and complete a survey on the activities they feel are safe or unsafe for each type of dwarfism (dependent, of course, on severity). When the results are published (a copy will appear in LPA Today and the Parents' Forum), this will be helpful to all of us. Up until now, I have heard many varied responses from the physicians on the board at LPA medical

seminars. For example, one doctor will tell us that soccer is OK for young achondroplasts. He is opposed, however to the rough, high impact, and highly competitive soccer that older children play. Another physician will tell us it is better not to let our children play any soccer at all, even in the early years. He feels it is too difficult, and very unfair, to make a child quit soccer once he/she reaches the age where the sport becomes too rough to continue. That same physician uses this philosophy when it comes to skateboarding. He feels that simple skateboarding may be safe, but trick skateboarding is definitely not. He feels that it is better not to start any skateboarding at all, because it's too difficult to keep your children from moving on up to dangerous trick skating.

When my daughters entered public school this year for the first grade, I dug out all my notes from LPA medical seminars to put together a modified Physical Education program for the girls (both girls have achondroplasia). I knew the school would need guidance in this area and I wanted to be sure that my daughters could participate in challenging, safe and appropriate activities. I presented my write-up (see below) to three physicians who specialize in dwarfism, two of whom are on LPA's Medical Advisory Board. They were Dr. Scott from the duPont Center in Delaware, Dr. Francomano and Dr. Sponseller from John Hopkins in Baltimore, MD. All felt that my write-up was appropriate and can be presented to any school as a guide in planning PE programs for achondroplastic dwarfs. The only point in which there was not total agreement was on "push-ups". One physician felt that this can possibly dislocate an elbow, as arms were not meant to extend all the way out. Another physician felt that push-ups are not a problem. While I was trying to decide whether or not to include this, one of my daughters dislocated her elbow just by leaning improperly on a table. So I decided to include pushups in my write-up for a modified PE plan, after all.

The write-up below was included as part of my two daughters' IEP's (Individualized Education Plans), although a similar plan could still be used informally, without an IEP, to assist a Physical Education teacher in working with your child. Our IEP's specifically state that our daughters are "eligible for Physically Impaired, require seat belts on buses, adaptations in the classrooms, and a modified Physical Education program." Attached to the IEP is my write-up on the specific

adaptations they require in the classroom and restrooms, and the modified PE program you see below. My local pediatrician signed off on both the adaptations and the PE program. I then met with the PE instructors prior to the first day of school and discussed the modifications and restrictions. They were very supportive. Lauren and Tricia's PE experience, so far, has been a very positive one, and they thoroughly enjoy this class. They have been assigned shorter distances to run, and a different exercise to do if they cannot do a particular activity. They never sit on the sidelines. Here is what made all of this possible. We hope it will give you some tips to use in preparing your own child's school program.

MODIFIED PHYSICAL EDUCATION PROGRAM FOR ACHONDROPLASTIC DWARFS

*(For Lauren and Tricia Mayeux - Pasadena
Elementary School)*

Achondroplastic dwarfs have spines that are susceptible to trauma. This is because there is a narrow opening of the foramen magnum where the spinal cord travels through at the base of the skull. Additionally, achondroplastic children have short limbs and a larger than average size head. These characteristics call for some restrictions in the area of Physical Education. With a few minor modifications, however, a child with this condition should be able to participate in a regular P.E. class with her peers.

Because of the spine's susceptibility, it is recommended that the child avoid activities where she might fall from a height. Climbing monkey bars should not be attempted without the assistance of an adult. Trampoline jumping should be avoided as should any activity that might cause extreme jarring or risk a bad fall. High impact contact sports such as soccer or football should also be avoided. Tumbling, cartwheels, acrobatics or gymnastics should be prohibited, as they can put a strain on the spine in the neck area. Normal running and jumping is perfectly fine.

Because these children's limbs are short, they must take 3 or 4 steps for every one step another child walks or runs. If the children run laps, they should be given shorter distances to run (i.e. one

lap instead of two or three). They may not be able to keep up with the other children when running out to the PE field and should be allowed extra time to get there, if necessary. Because their limbs are short and the head is heavy, they may fall frequently while walking or running. This is normal, and other than an occasional skinned knee, is not generally cause for concern. Being disproportionate makes some exercises difficult or impossible to do - such as sit-ups. Please modify or find an alternate exercise the child can physically manage.

An achondroplastic dwarf's arms do not fully extend. Any effort to pull the arm straight out can easily cause the elbow or the shoulder to become dislocated. Therefore pull-ups or hanging from monkey bars should be avoided. Certainly other children should not be allowed to hold them by the arms and swing them around in circles. Push-ups should also be avoided.

Because of an achondroplastic dwarf's size, the school may need to adapt some of the equipment used so that they can participate equally with the other children (i.e. smaller bat, shortened field hockey stick, or throwing a tennis ball instead of a softball - because of tiny fingers.)

One last consideration which applies to participation in all classes - - Please do not allow other children to "pick them up". There is a natural tendency for classmates to do this because achondroplastic dwarfs are so small. This is very dangerous however, and classmates should be advised strongly against doing this. If something is out of reach, a stool or chair should be used in all instances, rather than lifting the child.

The Mayeux girls participate actively in dwarf athletics (running track races, bicycle races, soft discuss throwing, club throwing, etc.) They take swimming lessons and tap and ballet classes. They are active children and should be in a regular PE class, along with their classmates, provided the minor modifications listed above are put into place. The goal should be to make the program challenging, safe and with attainable goals.