

TAR Syndrome - What Is It?

By Jeannde Hersom

T=Thrombocyto = low blood platelets – penia = not very much

A = asplasia or absence

R = radius

Characteristic: the absence of the radius or long bone on the thumb side of the forearm.

Thrombocytopenia - absent radius (*TAR*) is a rare condition that can be detected by ultra sound as early as eighteen weeks in utero. The ultrasound may detect the absence of the radii and other limb deformities. However, in some situations, it is not detected, due to its rarity, until after birth. Such was the case with Izzy.

TAR is considered a congenital abnormality since the bone structure is abnormal at birth. Viral illness and other stressful conditions such as surgery can cause a drop in the level of platelets and may even require a platelet transfusion. With maturity the problem of platelet episodes lessens. Approximately 90% of individuals with *TAR* are symptomatic during the first year of life with possible bleeding from GI tract or even bleeding into the brain. The level of platelets will fall and rise during platelet episodes. Platelets are needed when injury occurs so that the blood can clot. This process is called coagulation. The platelets attach to the injured tissue by clumping together and act as a temporary patch. The platelets then release an enzyme called thromboplastin which acts to cleave a particle. Bleeding can also occur inside the body such as the kidney, lung, and brain.

There are additional problems other than platelets such as leukaemoid reaction, which most often occurs in early infancy along with low platelets in a very sick child. Another is when an individual with *TAR* bone marrow makes too much of one type of blood cell called eosinophil. This is usually associated with allergies to cow's milk and can cause an increase in eosinophils.

GENETIC PROFILE

TAR syndrome is most likely an autosomal recessive disorder. Autosomal means that both the male and female can carry the genetic condition. Recessive means that both parents would be carriers of a single copy of the responsible gene. Autosomal recessive disorders occur when a person inherits a particular pair of genes, which do not work correctly. The chance that this would happen to children of carrier parents is 25% or 1 in 4 pregnancies.



Pilates and TARS ~ Making a Connection

When I met Izzy for the first time I didn't acknowledge what she did not have. I suppose like most Pilates Instructors I only identified the possibilities. I immediately recognized an energetic six year-old with the heart of a dancer and the imagination of a budding artist. I have had the opportunity to teach children, teen, and preteen Pilates classes and this was a perfect opportunity for me to apply what I have learned through the years.

LISTING: Listing is something that I typically do with new clients if and when there is a question or a challenge that needs to be met. I list words that come to mind when I think about that particular client

following our first meeting. Within that list, there will be a direction for me to consider. The list is not to be used in place of anatomical knowledge nor is it necessary to hold to as time goes on. Listing is merely a tool that I use in order to stimulate the intuitive process. As a teacher, one must instinctively trust oneself and above all else be willing to adjust to error. In Izzy's case, I needed a framework in which to define her capabilities both emotionally and physically...I needed a place to start.

GETTING STARTED: First, the research. Unfortunately, there is not much information from which to draw. So little is understood concerning this syndrome because each child's case is unique. The information that I did find was of little to no help when working with Izzy who also had extremely low muscle tone. Low muscle tone is not typically equated with TAR. I am the director of the Pilates program at a performing arts center where Izzy's mother came to me. She had the idea that the discipline of Pilates could be effective for children with TAR since the common denominator with these children is their core. I agreed that it was something to explore if she understood that I had never worked with it before. We agreed to try.

I prefer to go into all new situations with no preconceived ideas. I enjoy the process of discovery and have learned through the years that the client enjoys that journey as well. The relationship that develops from that is lasting. Izzy was my next client. I looked forward to all that I could teach her and her me.

BALLOONS, COCOONS, CATERPILLARS & WINGS: I have been working with Izzy for three years. She is now nine years old and understands the more traditional basic anatomical terms; however, in the beginning, when working with children the more familiar, treasured images of childhood are better suited, and a lot more fun! This technique is similar to using analogies and imagery when working with adults.

Izzy needed to understand on some level the physiology of her body, and what better way to start but with something that she knew as vital; breathing. I used the image of a balloon. I coupled that with a basic drawing of a diaphragm establishing its relationship to the rib cage and its size proportionately. The majority of people breathe into their chests or stomachs. In Izzy's case, she was breathing by raising her shoulders. Her forearms are foreshortened, and this was how she performed many tasks that required upper body strength. I discovered that for her it took effort to breathe. The image of a *balloon* inflating was successful. In a relatively short period of time, she was able to connect my cues with her body's actions. When she first came to me, her mother confided in me that there would be times when Izzy would not make it to her class because of respiratory-related illness such as pneumonia. In the three years that Izzy has been with me, she has rarely missed a class. Learning the process of correct breathing in relation to Pilates, I am happy to report, significantly improved her health. She hasn't had an upper-respiratory infection since she began working with me.

The *caterpillar*, our next image, represents the spine. I would always have a simple anatomical drawing on hand to connect the imaginary with the body. I also like to stimulate as many senses as possible when working with a client, and in this case, I used the sense of touch. I would run my finger up Izzy's back so she could get a sense of how long the caterpillar was. When working with someone who is uncomfortable with being touched, reverse the roles. I'm not sure how a real caterpillar moves but the Pilates caterpillar moves because



there are muscles between each of the vertebrae. Recognizing that all children are at least a little competitive and using that to my advantage in teaching her, I introduced her to the *energy wand*, anatomically known as the pointer finger. I sat crisscross style and invited her to draw an energy line up my spine, paying attention to how it lengthens. I challenged her to do the same. Using the energy wand later developed into a gentle brushing of my hand in the direction of lengthening. This is not unlike what I do with my adult clients. Izzy's understanding of lengthening and sequencing the muscles was a precursor to Bridging, Pelvic Bowel, Rolling Like a Ball, Roll Ups, etc. She is now quite a champ in doing all of those. Perfecting them is now the objective.

The *cocoon* represents the core. You might be thinking that I should have started there. On the first day, frankly, I thought the very same thing. I always have a plan in place for a class or workshop; the same is true when preparing for a client. That being said, one must always be prepared to change said plan and go with your gut should the situation warrant it. In Izzy's case, I needed to begin with things that she could see move, i.e., breath, (*the movement of the ribcage*) or touch (*the spine*). Stimulating her senses in relation to my cueing was essential for her experience to effectively manifest the proper outcome for the exercises while keeping her interested. Because of her extremely low muscle tone, the concept of the core as a group of muscles was very difficult for her to grasp. Above all else, at this point, it was significant for her to feel successful; thus building confidence. Izzy could very easily relate to the image of a *cocoon* and she therefore innately knew that something beautiful was going to emerge from her understanding. It took a little time, just like all good things, but through her hard work and the appropriate progressive exercises, the cocoon image slowly metamorphosed into the image of the core.

The scapula or *wings* used her shoulders body as I mentioned arms, the raising of movement. The would hold true Izzy could not pro-scapula. TAR also impossible. The low made them appear has had several op-her wrists over the hands turning in to the lel to the forearm, the



were the next image. Izzy when she moved her upper before. When she raised her her shoulders initiated same sequence of action when she circled her arms. tract or retract in the makes supination near to muscle tone in her arms floppy and uncontrolled. She erations on her arms to center ulna so that instead of her point that the thumb was paral-

hands are now in the correct position. Although the operations have improved her quality of life, they have possibly compromised her understanding and/or ability to organize the muscles. I wanted her to feel the connection of her arms to her back, targeting the movement in the scapula. I decided to present her with another challenge... "Izzy, butterflies don't have shoulders and if they don't, how do they accomplish the movement of flight or in this case Arm Circles?" I had her put her hands on my scapula to feel how the wings can move. We traded and I put my hands on her and, with a swipe of the energy wand giving her direction, she was flying.

Izzy had accomplished isolation of movements with different parts of her body. Her willingness to learn, the proper imagery, stimulating her senses, and getting a fuller understanding of the possibilities by mimicking my movements collectively became a winning combination.

Getting Going - The Exercises

I began working with Izzy in January of 2005. I started with the fundamentals of Mat work using the imagery. As time went on, the imagery and analogies matured and basic anatomy was introduced and is still being developed. The Mat work has been integrated with props such as a Magic Circle, Bands, weights, and small balls. The door is always open for new props or tools to incorporate balance into Izzy's workout. This past summer, we began work on the Reformer, Cadillac and Wunda Chair. I took into consideration the time that we have worked together and her height.

MAT

BREATHING - Izzy has done this both in a flexed forward sitting position, which encourages the breath into the sides and back of the ribcage and supine with knees bent, feet flat, arms at the sides. The foreshortening of Izzy's arms and the impact that it has had on her scapula made it uncomfortable initially to have her arms at her sides. She prefers to keep her arms over her head when in supine. We compromised with them on her tummy. She now has the mobility to have them at her sides or across her tummy, depending on the exercise. Practicing breathing in the sitting position, leaning towards the bent knees, is something that I have used in my adult Fundamentals classes because the breath has difficulty entering the upper chest or the abdominal cavity in this position. Sitting in a neutral position with an even weight on the sitz-bones, Izzy relaxes her arms at her sides, exhales as she sequentially rolls until her forehead rests on bent knees. Staying in this position, she inhales into her sides and the back of the ribcage expands. Repeat 3 to 5Xs.

We now focus primarily on breathing in the supine position. Izzy is now familiar with how that relates to the abdominal musculature (*Cocoon*). It is premature to be discussing pelvic floor principles with her.

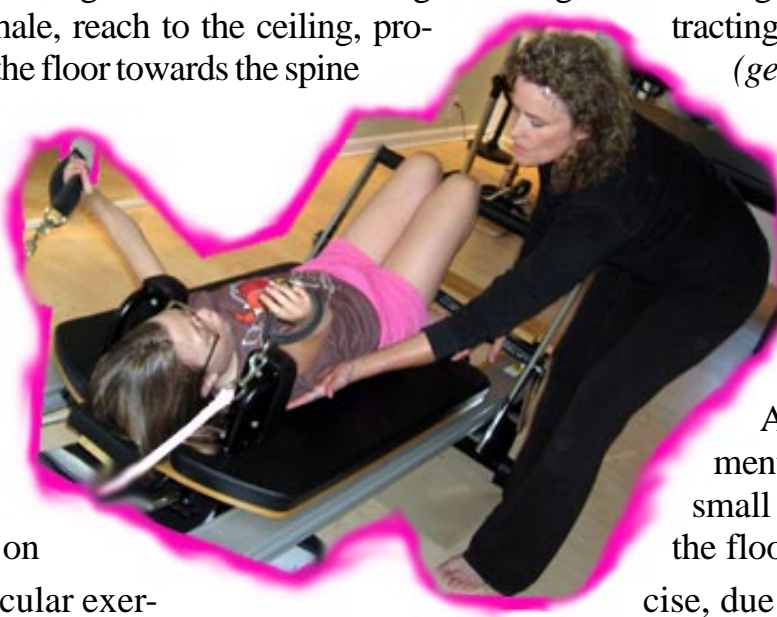
KNEE SWAYS - Begin with inhale, exhale on sway. Inhale drawing up the core muscles like a zipper to draw the knees back to center. 2Xs

KNEE SWAYS w/EXTENSION - Starting with an inhale, exhale on the sway, inhale on the extension, exhale while returning to the initial position. The return must engage the obliques and transverse. The legs should maintain the same distance between the knees. Repeat 6 Xs

ARM REACH - Supine, neutral, legs folded, arms reaching to ceiling, hands facing each other scapula in a neutral position. With an inhale, reach to the ceiling, protracting the scapula. Exhale, bringing the shoulders back to the floor towards the spine (*gently*). On the exhale, return to neutral. Repeat 4Xs

SHOULDER SHRUGS - folded legs, feet hip distance shrug the shoulders up to- With an exhale lengthen the head creating a greater the ear lobe and the shoulder depression of the scapula). paid to the correct chin alignment done with an open palm on rolling the ball up and down on

PELVIC BOWL - This particular exercise amount of concentration was very challenging for Izzy. We broke it down into a clock face 12, 3, 6 and 9, working on the 12:00 and 6:00 first. Gradually she put it all together and is now working on understanding the feeling of isolating movements, which becomes clearer as more mobility is accomplished. 4Xs



Supine, neutral, apart. With inhale towards the ears. arms away form distance between der (*elevation and Attention should be ment. This also can be small weighed balls, i.e., the floor. Repeat 6xs*

exercise, due to the considerable

BRIDGING - This exercise was challenging because it requires the lifting up of body weight, which proves difficult with low muscle tone but very rewarding with perseverance. Izzy and I are always working on clarity and just what the spine is capable of. Sometimes we will just stop and experiment with all the different ways it can move like a caterpillar. 4Xs

HUNDREDS - Izzy has been working on Hundreds and is continually getting stronger. With the proper modifications in place, she is gradually mastering them.

ROLL UPS - Roll Ups are a favorite of Izzy's. The goal in this particular exercise at this time is to be sure that she is using the core muscles to their fullest. 4-6 Xs

SPINE STRETCH w/Magic Circle - Recently Izzy has started to use the Circle during some of her exercises. During Spine Stretch, she will push on the ring as she is flexed forward towards her feet. This would be impossible if she did not have a handle on neutral and the stabilization on the scapula. It adds more challenge to the core muscles when articulating through the spine back to the starting position. The use of the ring in this exercise is initiated with us sitting facing each other, each with a ring. We begin by gently pumping them into the floor, careful not to use the arms. We oftentimes will have a little competition to see who can get the correct form first. Another tool that I use is role playing. I pretend to be the student and Izzy the teacher, so that she is able to correct me during the exercise. 4Xs

WEIGHTS 1lb - Sitting cross-legged, neu- initially was done without her scapula so she could scapula. Her scapular mobil- *trapezius, rhomboids, leva-* It became apparent that de- *tus anterior*), abduction (*ser-* *rhomboids*), upward rotation downward rotation (*rhomboids*, tively immobile. Izzy's arms are challenges. Understanding the process of Pilates has enabled her to make remarkable strides. The knowl- edge of how her muscles are functioning in relation to her arms helped me to evaluate her and make a plan targeting the shoulder girdle. Izzy has accomplished a great deal of mobility in the scapula (*But-* *terfly Wings*). Using the weights is tiring for Izzy, so this exercise is done for a short period of time depending on her level of frustration.



tral spine, Izzy lifts the weights. This weights. I would put my open hand on move her arms while stabilizing the ity was primarily in elevation (*upper* *tor scapulae*) for nearly all the exercises. pression (*lower trapezius, lower serra-* *ratus anterior*), adduction (*trapezius,* (*serratus anterior upper trapezius*) and *levelator scapulae*) seemed to be collec- two different lengths, which poses many chal-

ROLLING LIKE A BALL - another of her favorites. 4-6Xs

LEG CIRCLES - Initiate with the ankles both directions 3Xs, from the hip 2-Xs each direction. This was a very significant exercise in the beginning, challenging Izzy's coordination.

SIDE KICKS - We are just beginning side work with modifications primarily due to the length of her arms. Restrictions and variances affect each side. 4Xs

STRETCHING - When we first began to stretch it was difficult for Izzy to make the connection as well as she does now. Her body awareness has improved so much that she now can feel the muscles that she has been working so hard to develop. Without the muscle tone, prior to Pilates that awareness was unavailable. Izzy's mother gives me valuable information concerning what we should be working on regarding stretching. Izzy's physicians have various concerns regarding certain muscles not being stimulated. Communication is essential.

LUCKY GIRL

There are many limb abnormalities associated with TAR both in the shoulder girdle and the pelvis and hip joints. Some cases may be affected mildly, presenting with radial aplasia associated with varying degrees of hypoplasia of the ulna and humerus. These cases tend to have a near normal shoulder girdle and therefore the capabilities of near normal upper body strength. The second group is moderately affected with a greater degree of limb shortening and hypoplasia of the humerus associated with underdevelopment of the shoulder girdle and reduced strength. In both these groups pronation and supination difficulties are a factor, and splints are often found useful for prolonged periods of upper limb activity. Izzy is challenged with both pronation and supination. She is getting much stronger in the shoulder girdle since she began Pilates. She wore splints 24/7 until she was in the third grade and now wears them primarily at night. She refers to them as her bracelets. The length difference in her arms is a factor; however, she will be going through surgery in the near future to lengthen the left arm. The legs may also be affected. The hips can become dislocated so that the femur does not sit properly into the socket. Abnormalities in the knee can cause abnormal bending one way or the other, loose kneecaps or possibly knees slipping on each other. Sometimes the knees can be fused. Frequently there are abnormalities in the toes and or puffiness in the feet. Izzy's greatest challenge was to become aware and control what her body could do. My job was to view structurally an uneven skeletal system with all the variances in the muscles and ligaments, etc. Through palpitation and intuitive thinking, I came to understand her abilities. She learned how to move properly in accordance with the resources that Pilates could offer. Izzy has now tapped into a new resource of strength. She has found a balance in herself by using the spinal column as the axis, the center from which to work. She is extremely fortunate with what she has and the undeniable support of her family.



A NEW CHAPTER

I have just begun working with Izzy this summer on the apparatus. It was necessary to wait until she was tall enough and it was essential that she understood the fundamental principles of Pilates. One must be very alert when introducing the apparatus work to someone so young and challenged.

REFORMER

1. Footwork: Toe Curls, Arches, Heels, First Position, Heel Lowers, Second Position, Running
2. Hundreds
3. Arm Circles (*strap adjustment*)
4. Leg Circles
5. Short Box: Round Back, Arm work (*facing back*)

CHAIR

1. Leg Pumps

CADILLAC

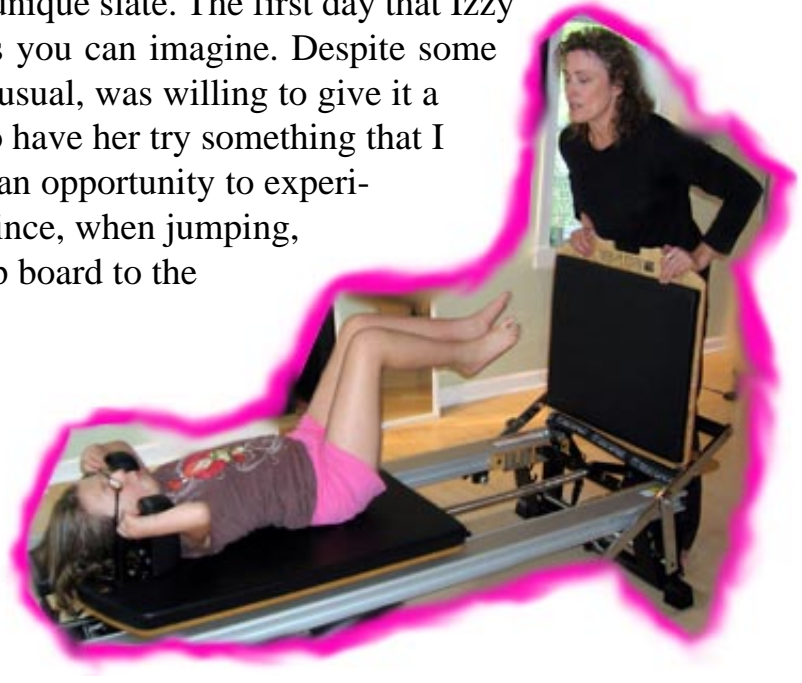
1. Roll Back
2. Forward Push Through
3. Pull Downs-sitting sideways using bar down focusing on scapula mobilization



This unique opportunity to integrate a new level of strength and coordination into her regime has been exciting. Having the various machines and her marvelous attitude enables her to adapt. Now, little by little, a new horizon - quality of movement - can be re-examined.

Working with Izzy these last few years has never been about reeducating her since she is so young. It has always been about working from a clean and unique slate. The first day that Izzy worked on the machines, she sat there timidly as you can imagine. Despite some trepidation about getting on the Reformer she, as usual, was willing to give it a try. By then she had gained my trust. I did want to have her try something that I thought she would enjoy and perhaps never have an opportunity to experience to the degree that she could on a Reformer since, when jumping, gravity is eliminated on joints. I attached the jump board to the Reformer and carefully explained to Izzy that she could jump really high, something that she had never experienced.

We started by rolling gently back and forth, bending her knees. I, of course, kept my hands between her and the springs for safety. Within minutes, she understood the concept and with a breath, pushed off. There was only one thing missing - her butterfly wings - so the arms were quickly added. With a huge smile on her face she was off. What started as a little *cocoon* three years earlier now was a beautiful *butterfly* soaring high off the ground using her newfound muscles.



Jeannde Hersom the Pilates Director at Mount Airy Performing Arts Center; also conducts workshops and teaches private clients in her home studio. She is certified in Mat and Apparatus and has been teaching Pilates for five years. For thirty years before entering the world of Pilates, she was a professional dancer and dance instructor. Jeannde is also a commissioned artist, specializing in acrylics and oils.