

about a boy

despite a devastating form of muscular dystrophy, david loughran is maintaining his mobility and strength, thanks to pilates

David Loughran is a lively 12-year-old from Princeton Junction, NJ, who loves joking around with his friends and three older siblings. An obsessive sports fan, he follows an eclectic roster of teams: the Philadelphia Eagles, the New Jersey Devils and the New York Yankees. Unless you were paying close attention, you wouldn't necessarily notice anything unusual about the lively seventh grader, except that he moves a bit like a power walker, propelling himself forward by putting most of his weight on his toes, heels barely touching the ground.

And yet there is something truly remarkable about David: At

toms are evident by the time they are 2 or 3," explains his mother, Jan. (DMD primarily affects male children, but, in rare cases, a mild form of the disorder affects females.) But David wasn't diag-

"A lot of boys with DMD walk late, but David walked at 11 months," Jan says. "I didn't notice anything unusual about him when he was in preschool, like the enlarged calves that we later learned are a common symptom. A lot of younger kids with DMD fall down frequently,



David gets a workout at Anthony's Princeton-based studio, June 2010. Top: Anthony leads a family mat class with David, Rory, Chris and Laura.

12½, an age at which most other sufferers of Duchenne muscular dystrophy (DMD) are confined to wheelchairs, he's getting around on his own two feet.

"With most boys, their DMD symp-

nosed until he was 6, after the school nurse called to say she had noticed that David didn't run, he power walked.

Up until that point, there were no other obvious symptoms of the disease.

but that wasn't the case with David." He did have a slightly unusual gait, but she attributed that to the fact that he liked to wear loafers.

Even after getting the call from the

PHOTOGRAPHY BY JANET LANZA

school nurse, neither Jan, a retired attorney, nor her husband, Chris, a bonds salesman, were alarmed. “I didn’t even look his symptoms up on the Internet because he seemed fine to me,” Jan says. “I figured he just needed some physical therapy, so I made an appointment at Children’s Specialized Hospital in Hamilton, NJ. I thought that I was making an appointment with a physical therapist, but when we got there, they told us that we would be seeing a neurologist. Still, I wasn’t worried.”

the road to discovery

The doctor asked David to lie on his stomach and then get up without using his hands. Like most boys with DMD, David couldn’t do it. Then the doctor took David’s shoes and tossed them to the end of the hallway. He asked David to go get his shoes while walking on his heels. He couldn’t do that either. “At this point, David was getting agitated because he’s supercompetitive and didn’t like not being able to accomplish the tasks,” Jan recalls. At the end of the appointment, the doctor told Jan that he thought David might have Becker, a form of muscular dystrophy.

Because this problem had a name, Jan realized that this was serious. To confirm the diagnosis, David’s blood was tested for an enzyme called creatine kinase, high levels of which indicate the muscle damage caused by muscular dystrophy. The lab sent the test results to the neurologist and David’s pediatrician. When Jan didn’t hear back from either, she called the pediatrician, who told her that David’s blood tests had in fact come back. “A normal level is generally below 200,” she explains. “David had over 50,000.” The doctor told her that the test results indicated that David didn’t have Becker muscular dystrophy, he had Duchenne, the most severe form.

With Duchenne, patients’ muscles weaken rapidly, the result of a defective

gene for dystrophin, a protein that helps keep muscle cells intact. But with this condition, muscle tissue doesn’t regenerate and continues to be damaged; the muscle “bulk” is reduced and replaced with fat and excessive scar tissue (which causes the signature enlarged calves). Although two-thirds of the cases of

cle cells die all the time,” Chris explains. “Steroids help by reducing inflammation.” David also started going to physical therapy once a week.

“There are protocols for therapy for Duchenne,” Chris continues, “including certain exercises you shouldn’t do, as they could cause more muscle destruction.

The physical therapists understand David’s challenges and have developed exercises that are fun for David and help him retain as much muscle strength and flexibility as possible.”

To help keep him ambulatory, David walks on an elliptical machine for five to six minutes and works on picking his feet up with his quads. “They’ve really helped him maintain his flexibility and coordination.”

At home, Chris does a 10-minute stretching routine with David every night. “David can’t lift his own leg, so I lift it, bend it at his knee and push his knee toward his shoulder to stretch his glutes. He also does calf stretches on a 45-degree incline

board. As cells die, his muscles start constricting over time, so we fight that with stretches. Doing them every day is the most effective way to combat that constriction—plus it feels good to David.”

In addition, David swims several times a week (his siblings are all competitive swimmers). Jan and Chris have also looked for ways for David to participate in other activities. A neighbor invited David to be the statistician for his son’s sixth-grade basketball team. And David stays active in other ways: He’s performed in a summer theater production and is a very conscientious student. In fact, he may be one of the few middle-schoolers who does his homework as soon as he gets home without being prodded.

pilates 101

“Every year our local *Princeton Packet* runs a health and fitness insert,” Chris says. “In 2001 I had read about Anthony Rabara’s Pilates studio, which got great



Top row, from left: Anthony, Shannon, Jan and Chris. Seated: Rory, David and Laura

DMD are hereditary, in the rest of the cases (including David’s), it is the result of a spontaneous genetic mutation.

Most boys with DMD start having difficulty walking when they are preschoolers and are prone to falling. By 12, most use a wheelchair; few live beyond age 30. There is no known cure for Duchenne, but treatments, including steroids and physical therapy, can keep patients mobile and improve their quality of life.

an action plan

Immediately after learning of the diagnosis, Jan called her college roommate, a pediatric anesthesiologist at Johns Hopkins. “She contacted some colleagues and within a few hours gave me the names of good neurologists.” They ended up choosing Richard Finkel, MD, at Children’s Hospital of Philadelphia.

Finkel examined David and recommended a course of prednisone, a steroid that combats inflammation and slows disease progression. “David’s mus-

reviews. I thought that I should give it a try, but I never got around to it. In 2006, about a year after David's diagnosis, I happened to be going through that year's insert, saw another review of Anthony's studio and thought, *I wonder if he can help David?*

"I had read that Pilates helps strengthen the core muscles, and I

thought that it might help David maintain balance and compensate for the muscles that were losing strength. So I called Anthony and explained the situation. He told me to bring him in on Saturday and that he'd take a look at him and see what we might be able to do together."

Anthony spent that first session assessing David's strength and range of movement. "David didn't have any core strength," Chris notes, "but that's typical

for a little boy. Anthony had him do some exercises on the mat, then some moves on the Cadillac. Anthony realized if someone with MD tears a muscle, it doesn't regenerate, so he was extremely gentle with David." (For more details on Anthony's work with David, see below.)

Anthony and his instructors quickly embraced David. They made the sessions fun as well as challenging.

working with people with MD

David's Pilates instructor is Anthony Rabara, owner of Anthony Rabara Pilates Studio of Princeton. Rabara has been teaching the method since 1983 and is now a teacher-trainer for Romana's Pilates. He works with everyone from Olympic athletes and professional dancers to "regular" people and those with special needs, which seems to be one of his specialties. We asked him to discuss his work with David and what other pros need to know when working with clients with muscular dystrophy.

I started working with David about four years ago. At that time he was very mobile but used the Gower's Maneuver [see below] to get up, which is typical of MD

Anthony and apprentice Mindy Lafferty assist with Gower's Maneuver



patients. With Gower's, people start on their hands and knees, and use their hands to "walk" up to a squat.

Our goals were to build core strength, improve muscle and joint function and slow muscle deterioration so that David could stay upright and mobile as long as possible. Toward that end, in every session we do elements of the mat: the Hundred, Roll-Up or Rolldown, balancing in a rolling posi-

tion, Single-Leg Stretches, Criss-Cross and Side Kicks. Because MD patients toe-walk, we work on heel- and calf-stretch exercises like Footwork on the Reformer.

On the Cadillac, David works with the rollback bar for spine articulation and with the leg springs to lengthen and strengthen his thighs and calves. We pay a lot of attention to scooping his belly for spine stability, which is paramount in minimizing scoliosis. He also extends his spine by Swimming on a large ball, balancing his body while moving his legs and arms. (Though we don't use a ball in traditional Pilates, it's a perfect way for a boy his size to balance on his stomach while arching his upper back.) David also uses the Reformer and the Electric Chair for leg pumping to keep his quads strong and his knees tracking properly.

In the beginning, David could get through eight to 10 exercises. Today his repertoire is about twice that. I do not give praise easily, but it is an honor to work with him and his family. I've learned a lot about working with children with MD, and here's my advice for helping them:

- See the child first, not the disease. Make sure they feel valued and safe.
- Ask the parent how much the child can do and look to him or her to help you.
- Be cautious about range of motion. Don't take their limbs too far out of the "box"—keep their arms within the width of shoulders and legs within width of their hips.
- Be extra-sensitive to energy levels. We

take one-minute breaks as needed throughout the session. You don't want to exhaust clients so they're in bed the rest of the day, which is counterproductive to our goal of getting them to move as much as possible.

- Focus on core building and overall strength building more than stretching. Calf muscles and the torso, however, need to be lengthened. Each client is different, so use your judgment.



- Be prepared to help children onto larger apparatus like the Cadillac and Electric Chair. When you lift them, hold them around the stomach or hips to avoid having your hands slip and injure their shoulders.
- Learn about gait and how to apply the child's current motor skills to exercises you might give him/her.
- Use our mantra "in and up" to help the child understand the

concept of lifting out of his or her hips and legs. Children who are able to support more of their weight with their core muscles are likely to stay mobile longer.

- Know your tools: Use the foot straps for their Roll-Up or Rolldown, the head pillow when he has trouble elongating his neck or lifting his head from a lying position.
- Keep light weights handy to help with arm strength.
- Have fun! Let them play. Sometimes David will be making up movements on the Cadillac or another apparatus, and I will turn his inventions into exercises to give our sessions a sense of fun and creativity.

—Anthony Rabara

One day one of the instructors, Andrea, was working with David, encouraging him toward the end of the Hundred. "She said, 'C'mon David, you can do it, just 10 more,'" Chris recalls. "David wasn't sure he could finish and blurted out,



'But I'm just a little boy!' Well, the group of us broke out laughing, as did David.

"Another time David said, 'Spare me the drama.' I thought, *Where did he come up with that?* I gave David a stern look and asked, 'What did you say?' David pointed to a sign Anthony keeps in his office and said, 'I was just reading that sign.' So now whenever David wants a short break, he says, 'I'm just a little boy' and Anthony says, 'Spare me the drama!' Their personal chemistry is excellent."

the proof of the pudding

Six months after David started with Anthony, he had an appointment with Finkel, the neurologist. David was on the exam table, and Finkel asked him to hold his head up; he was very pleased when David could do so unassisted for more than a minute. When Finkel checked his abdomen, he said, "David, you have some muscles here!" David got a big smile on his face and said, "That's because I do Pilates!" With that encouragement, David was eager to continue. He is now in his fourth year of Pilates.

Today David is still walking, though at a slower-than-normal pace. It's a struggle, but he can even climb the 14 stairs at his family's house using the handrails. "Pilates has made a difference in David's mobility, quality of life and self-esteem," says Chris. Everyone at the studio knows David, and several people have told Chris that David is an inspiration for them. "David's really proud of that." ☺



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