

Steady Hand

Tourette's syndrome hasn't stopped pro soccer player Tim Howard from becoming one of the best goalkeepers in the game.

BY TODD FARLEY

Few people understand the stigma of Tourette's syndrome (TS) as well as Tim Howard, whose condition was mocked by the English press when the American goalkeeper first moved overseas to play for professional club Manchester United in 2003. A longtime stalwart for the U.S. World Cup soccer team who now plays with pro club Everton, Howard was often called "retarded" by British tabloids because of his TS.

Today, Howard brushes off those slights as "ignorance" on the part of people trying to sell newspapers. But those headlines were not the only way Howard's condition was remarked on publicly. English fans traditionally make up

ing so far as to call the Manchester chant a "warm embrace" of his condition—they exemplify both the stigma TS can entail and the misunderstanding that many people have about the symptoms.

CHRONIC TICS

In fact, TS is a neurologic disorder defined by chronic tics. A tic is a sudden, repeated, involuntary movement of the body or vocalization. "To be diagnosed with TS, a person must have had both motor and vocal tics for more than a year," says Harvey Singer, M.D., Haller Professor of Pediatric Neurology at Johns Hopkins University School of Medicine and a Fellow of the American Academy of Neurology (AAN). "Other criteria include that the disorder would have started before age 21, that there is a waxing and waning of various tics, and that the condition doesn't result from medication or another disease." (See box, "Tourette's Syndrome: The Basics.")

Experiencing only motor tics is known as "chronic motor tic disorder," while having only vocal tics is called "chronic vocal tic disorder." A TS diagnosis results only when a patient experiences both.

"Simple physical tics would be a blink, a shrug, a little jerk, or a head turn," Dr. Singer says. "The more complex physical tics might be when you're walking and suddenly spin or hop, or you put a whole variety of simple tics together into a more complex single movement," he says.

Dr. Singer lists "sounds, noises, grunts, barks, hoots, hollers, moans, groans, and throat-clearing" as simple vocal tics, but he says the more complex vocal tics normally involve the use of words. These include repeating one's own words continually (palilalia), repeating the words of others (echolalia), or, most notoriously, uttering obscene or inappropriate words aloud (coprolalia). While it is coprolalia that many people equate with TS, as few as 15 percent of individuals diagnosed with TS actually experience that symptom.



GOAL KEEPER Tim Howard training with the U.S. Men's National Soccer Team in Washington, D.C., 2012.

songs about players on the field. While Howard's nationality is frequently targeted in the songs about him, so is his TS. In fact, Howard's own fans at Manchester United concluded their chant about Tim—sung to the tune of "Chim, Chim, Cher-ee" from *Mary Poppins*—with the chorus, "Tim, Tim, Timery... says F--- you!"

While Howard is able to laugh off the songs—even go-

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— DONALD GILBERT, M.D.



“It used to be thought that coprolalia was a common symptom of TS,” says Donald Gilbert, M.D., associate professor of pediatrics and neurology at Cincinnati Children’s Hospital Medical Center and Fellow of the AAN. “But now that more people are being accurately diagnosed, we realize that just a small fraction of people with TS have complex tics such as swearing or inappropriate gestures such as giving the finger.”

Tourette’s Syndrome: The Basics

What Is Tourette’s syndrome? Tourette’s syndrome (TS) is a disorder of the nervous system characterized by repetitive, involuntary tics. An official diagnosis occurs when someone has chronic motor and vocal tics lasting more than one year. TS begins in childhood, on average at about age seven. Symptoms may worsen through the teen years and sometimes persist into adulthood, but frequently they lessen with age.

What are the symptoms of TS? The characteristic symptoms of TS are tics, which can range from mild to severe and are classified as either simple or complex. Simple tics involve a limited number of muscle groups; complex tics entail larger, more coordinated patterns of movement. Examples of these tics include blinking of the eyes, shrugging of the shoulders, and jerking of the head. Rare cases include the uncontrollable urge to swear aloud (coprolalia) or even harmful things like punching oneself.

How common is TS? Because TS is diagnosed clinically and often occurs along with conditions like ADHD and OCD, the exact number of people affected is not known. It is suggested that between 1 to 3 percent of people around the world are affected by TS.

What treatments are available for TS? Not everyone with TS needs to be treated for it, depending on the severity of the tics and the amount they interfere with one’s life. Treatment options that do exist, however, include both behavioral and pharmaceutical therapies. The behavioral therapy most in use today is comprehensive behavioral intervention for tics (CBIT), in which patients are taught how to control the urge that leads to their tics. Pharmaceutical therapies include medicines created for lowering blood pressure (guanfacine and clonidine), and two anti-psychotic drugs (haloperidol and pimozide), all of which have helped reduce tics in many cases.

ASSOCIATED CONDITIONS

The exact number of people with TS is not known, although recent studies suggest between 1 and 3 percent of people around the world have TS—including three or four times more males than females. A little-known reality about TS is the frequent presence of associated disorders.

“People with TS often have associated problems,” Dr. Singer explains. He notes obsessive-compulsive disorder (OCD) and attention deficit hyperactivity disorder (ADHD) as the two most common, but anxiety and depression are also seen often with TS.

To be officially diagnosed with TS, the symptoms of the disorder must begin before age 21, but in most cases they begin at a much younger age, as happened in Howard’s case. Growing up in New Jersey, Howard first began to notice symptoms between the ages of 8 and 10. “It’s hard to pinpoint the morning I woke up and things were different,” he says. “Plus, the tics kicked in at the same time as the OCD.”

His OCD symptoms were initially more obvious. Howard recalls he felt the need to count any lines he saw (such as on a sheet of paper), to count the number of steps he was taking, to place his hand on and touch whomever he might be conversing with, or to pick up and carry home various small stones on his daily commute to and from school, for no other reason than “they just seemed to need to be picked up.” At home, walking from the kitchen to his bedroom, Howard had to go the same direction every time and touch the same items every time.

“It was normal stuff,” Howard says of his behavior. “Normal for someone with OCD.”

As for Howard’s tics, they were normal for someone with TS. “There’s been such a wide variety,” he says. “Blinking, head movement, tensing up of my upper body in particular, head shaking. . . .”

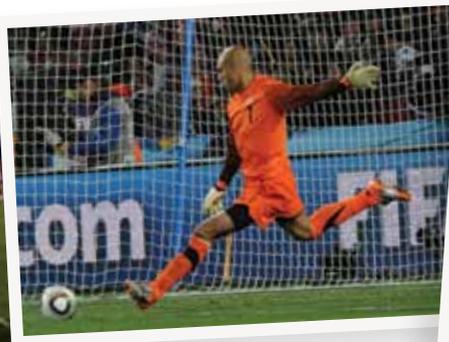
BEING A KID WITH TS

One hallmark of TS is the way the disorder waxes and wanes, which Howard certainly experienced. “From the age of 9 to 15, it was just this chaos of different tics, and they were pretty strong,” he says. “I would just begin to figure out how a tic worked with my body, and, bam, six months or a year later, a new tic would come.”

Howard acknowledges that living with such tics at a young age can be problematic, both academically and socially. “I enjoyed school, but I couldn’t sit still, didn’t have a ton of focus,” he says. “I was just trying to get myself in the moment.”

“And, of course, kids talk,” he says of growing up with condition. “Any time anything’s different about a kid, not just TS, they talk.”

Howard says he dealt with his condition simply by internalizing it. “If I was having a tough spot, one day, one week. . . I just went into my own shell, kept more to myself.”



A STAR ON ALL FIELDS
Left to right: Tim Howard stretching for a ball as keeper for the NY/NJ Metrostars in 2003; celebrating the U.S. National Team's qualification for the 2010 World Cup; taking a goal kick against Slovenia; and celebrating a win against Algeria.

Howard also realizes he was fortunate that bullying was never an issue for him, as he was “a big kid,” popular and athletic. “But also, I had such good friends,” he says. “They didn’t ostracize me or make me feel like an outcast.”

The benefits of sports were especially obvious in Howard’s case, as much for him as for his peers. “On the field I wasn’t Tim who had TS or Tim who had tics,” he says. “I was Tim who scored goals or scored baskets or hit home runs.”

DIAGNOSIS

While the symptoms of the disorder can be quite obvious, what happens in the brain of someone with TS is not so clear. “TS involves a change in signaling in the brain, but not really in the structure of the brain as far as we can see,” Dr. Gilbert explains. “So you can have the most severe case of TS and nothing will show up on a regular MRI or CT scan of the brain.”

A diagnosis of TS can therefore only come from an examination by a physician. “No diagnostic test, such as a blood test, exists,” Dr. Singer explains.

Most research indicates that TS results from a problem in the way neurons communicate.

“People who have movement disorders have some sort of disturbance in the basic pathways that allow you to activate movement,” Dr. Gilbert says. “In TS, the disturbance probably relates to blocking unwanted movements from occurring at inappropriate times.”

Problems in those pathways also helps explain why conditions like OCD and ADHD frequently occur along with TS. “These pathways are important for the motor system, but they’re also shared by the thinking and emotional systems,” Dr. Gilbert continues. “So the areas that are involved in releasing tics also result in problems controlling words or bad thoughts, regulating attention, and general level of impulse control.”

While the cause of TS is not yet known, genetics certainly seems to play a role. “It is highly heritable,” Dr. Gilbert says. “If one person in the family has it, often other people in the family will have it too.” However, says Dr. Haller, researchers are still trying to figure out how often TS appears among multiple members of the same family. “So far, the gene or genes involved are not known, but a great deal of research is being done to figure this out,” he notes.

TREATMENT

Howard has never been deterred by his condition. Growing up, his soccer skills led to him playing on U.S. national youth teams. In 1998, the 19-year-old Howard made his professional debut for the New York/New Jersey MetroStars of Major League Soccer (MLS). Howard eventually become an MLS All-Star and in 2001 was named the youngest ever MLS Goalkeeper of the

Year. He was also named the MLS Humanitarian of the Year based on his work creating awareness of TS. By 2003 he was on his way to England to mind the net for Manchester United, one of the biggest clubs in the world.

Throughout his life and career, Howard has opted not to take medication for his TS—a decision that is not unusual. “Just because you have tics doesn’t mean you have to take medicine,” Dr. Singer says.

At times, of course, treatment is necessary, whether due to emotional or social difficulties that result from a person’s tics or the physical pain that can also occur—for instance, when a tendency to continually jerk one’s neck leads to constant headaches. Dr. Gilbert says treatments for TS can begin with interventions at the school or workplace to educate people about the symptoms of TS and how to adapt to them. Further treatments include both drug and nondrug options.

While Howard has never taken tic-suppressant medication for his condition, he did visit a child psychologist. “At one point when I was young, I tried different meditative techniques in the evenings and mornings to manage it,” he says.

A similar treatment in use today is comprehensive behavioral intervention for tics (CBIT), in which people with TS are trained to overcome their tics with the help of a psychologist. The patient is taught to recognize the urge that often precedes a tic and works to produce a competing response, which ideally helps to reduce the original tic. “It’s a behavioral therapy component with an emphasis on habit reversal,” Dr. Singer says, adding that CBIT has proven to be as effective as some milder tic-suppressant medicines.

Neurologists often use one of two different kinds of medications to treat TS. The first are clonidine (brand names Kapvay or Nexiclon) and guanfacine (Tenex, Intuniv), two milder drugs with few long-term side effects. “Clonidine and guanfacine, two medicines that were brought on the market to lower blood pressure, sometimes help with tics as well as ADHD,” Dr. Gilbert says. (Both can cause low blood pressure, lightheadedness, dry mouth, dizziness, and constipation.) If those drugs don’t work, anticonvulsants such as topiramate (Topamax) may be used, although it can cause kidney stones and cognitive side effects such as difficulty concentrating.

In many cases, the medications that have proven most effective in dealing with tics carry more significant risks. “The only two medicines that are FDA-approved for use with tics are anti-psychotics,” Dr. Gilbert says of the neuroleptic drugs haloperidol (Haldol) and pimozide (Orap). “They’re used to treat excessive thoughts in schizophrenia but are also known to reduce tics.” While effective for TS at times, the side effects

TS is a neurologic disorder characterized by chronic tics. Most people equate it with **outbursts of profanity**, but as few as 15 percent of individuals diagnosed with TS actually experience that symptom.

of those anti-psychotics can also include sedation, weight gain, emotional changes, motor difficulties, endocrine problems, and the risk of tardive dyskinesia (involuntary, repetitive body movements).

In more extreme cases, deep brain stimulation (DBS) has also been shown to improve the symptoms of TS. DBS involves implanting electrodes into the brain to produce electrical currents that help control abnormal brain impulses. It is not FDA approved to treat TS and, like all surgeries, carries risks. But, according to Dr. Singer, it has been effective in treating TS that does not respond to CBIT or drugs.

COPING WITH AND WITHOUT MEDS

One of the best treatments for TS, however, may be patience, as the condition frequently ebbs with time. Dr. Singer cites studies that suggest TS will stop in one third of adults and improve in another third, with the remaining patients continuing to experience a disorder that will fluctuate, alternately getting better and worse.

“For the most part, it does decrease in adulthood,” Dr. Gilbert says.

Now in his early thirties, Howard has a case of TS that still manifests itself but has improved. Some of the tics of his youth remain (like tensing of his upper body) and he has new ones as well (including throat-clearing), but the tics do not vary as quickly as they did in his youth, and their effects are not so intense. “There’s neck movement, but it’s not as violent or vicious or sharp,” Howard says. “I also experience blinking, and head movement, but it’s not as severe as it once was.”

Howard’s tics have never affected him on the soccer field; in fact, they rarely affect people who are making purposeful movements. “If you’re focused on a practiced task like stopping a soccer shot,” Dr. Gilbert says, “that will override your circuits so you don’t tic.”

One thing that does exacerbate tics is stress, and Howard makes his career playing a high-pressure position in a high-profile sport—a job with millions of dollars on the line each game and millions of viewers watching on TV. Howard shrugs at the paradox of his chosen profession. “I notice the tics myself in the 24 hours leading up to game-time more than I do the 90 minutes on the field,” he says.

Ironically, there have been infamous instances in his playing career when Howard has been unable to hold his tongue, but probably not because of TS. Rather, he’s known for screaming directions

at his players, admitting that in the beginning of his career this yelling was little more than “gibberish.” Howard infamously called out Sir Alex Ferguson at Manchester United (arguably the most influential coach in the world) for not giving him enough playing time, and recently made international news by lashing out at one of the largest international soccer federations in a tirade that included an expletive or two. None of this may have anything to do with TS.

“No,” Howard says with a sheepish grin. “I think it’s just because I’m an outspoken and competitive guy.”



TEAM UP WITH TIM
Howard working with kids as a member of the board of directors for the NJ Center for Tourette Syndrome & Associated Disorders.

THE FUTURE

While researchers continue to work on trying to solve the mystery that is TS, much work remains to be done. According to Dr. Singer, genetic studies are underway to understand the disease process in the brain.

Dr. Singer also mentions the need for better therapies, as does Dr. Gilbert. “Nearly all the medicines discovered for TS were discovered by accident,” Gilbert says. “We need to have new medicines specific to TS rather than being for another disorder.”

As for Howard, he continues to play soccer at the highest level, even with TS. After three years at Manchester United (including being named to the league’s top 11 his first year), he moved on to the “greener pastures” of Everton, where he plays to this day. Howard also continues to guard the goal for the U.S. men’s national team, hoping to help guide the team to the 2014 World Cup in Brazil.

In addition, Howard faces his condition as bravely as he plays soccer, raising awareness of the realities of TS by doing advocacy work as a member of the board of directors for the NJ Center for Tourette Syndrome & Associated Disorders (njcts.org). He also speaks to children about the condition whenever he can, either through his Everton club or the U.S. national team. Howard recalls being impressed as a boy with the basketball player Chris Jackson, who excelled professionally while living with TS, and hopes to set a similar example on the soccer field.

“One of the biggest things I can do is be in the public eye,” he says. “It’s not like I even have to shout from the rooftops that I have TS. I’m on television, ticing and twitching. I think that’s kind of cool.”



For more information on Tourette’s Syndrome, see [RESOURCE CENTRAL](#) on page 37.