Should the results of genetic tests be protected under privacy law?

Guard Your Genetic Data from Those Prying Eyes

Dana Hawkins

Seven vials of blood is a lot. That was Janice Avary’s first thought when she heard that her husband Gary’s employer, the Burlington Northern Santa Fe railroad, was requiring that amount of blood to be taken after he filed claims for a carpal-tunnel injury. As a registered nurse in Alma, Neb., Avary says, her internal alarm was tripped. When she called the company for an explanation, Avary was stunned to hear the words “genetic test.”

Her queries led a railroad workers union this month to sue, seeking an end to the allegedly secret testing. BNSF says it has stopped the yearlong pilot program, but Gary Avary thinks that if his wife hadn’t asked, it would still be going on. “Unless you have a medical background, you wouldn’t know to ask these questions,” says Janice Avary.

DNA bias. The lawsuit—the first of its kind against a private employer—was filed just as scientists first published the map of the human genetic code. While genetic advances will likely lead more patients to seek cures for inherited diseases, they are also increasing worries among legal experts and patient rights groups about how genetic data will be used, both in the workplace and elsewhere. “There’s no question some employers are testing,” says Michael Werner, a lawyer for Bio, a group representing the biotech industry. “And as more tests are developed and the price drops, the market is expected to grow.” Even so, there are ways to protect your privacy in the workplace—or if you choose to be tested on your own.

A big concern among genetic experts is that results from such tests could be used to block someone from being hired or promoted, or to deny insurance. Already, there are hundreds of documented cases alleging genetic discrimination by employers and insurers. For example, preliminary results from a survey by the Genetic Alliance, a coalition of patient advocacy groups, show that 42 percent of 220 respondents claimed health insurance discrimination. Sixteen percent cited bias at work and in the military. The survey included such cases as a woman who alleged she was denied long-term disability insurance because the company said she had a predisposition for Alzheimer’s disease. Its decision was based on a doctor’s scribbled notation in her medical record that her father might have the condition. In another instance, after a first grader was diagnosed with a genetic developmental disorder, his mother’s employer eliminated the child’s healthcare coverage, saying the diagnosis qualified as a pre-existing condition.

Protect yourself. While federal workers are legally protected against genetic bias in health insurance and employment, private employees are not. Rep. Louise

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Slaughter, a New York Democrat, says support is building for legislation she cosponsored this month that would ban such discrimination. “Each of us has bad genes, and eventually they’ll all be identified with diseases,” says Slaughter. Even some genetic experts who advocate responsible testing, like Vivian Weinblatt, president of the National Society of Genetic Counselors, are advising patients to consider waiting for Congress to pass such a law before getting screened. “Ask yourself: Will knowing the results make my life better? Will I make different life choices? Can I wait a year?” says Weinblatt. If results will help you to treat or prevent a condition for which you’re currently at risk, like colon cancer, testing may be wise. If not, or if the results could be inconclusive, says Weinblatt, then it’s probably not worth the risk of a permanent flag on your medical record.

If you decide to test, experts offer this advice: Express any concerns to your physician or a genetic counselor and ask who would have access to your records. Find out whether your employer is self-insured, meaning your boss might get the bills. And consider buying life, health, and disability insurance before getting screened.

Question whether you really need to be tested. In some cases you might consider making the same lifestyle changes you’d make if you tested positive. Those with a family history of breast cancer, for example, might forgo genetic testing and instead be vigilant about regular breast exams. Also, be aware you may learn something you could later regret knowing. For instance, one of the tests for predisposition to heart disease may also reveal a risk for Alzheimer’s.

Finally, become familiar with the mechanics of testing. If your employer requires blood samples, get a list of the tests to be run. And ask what happens with the blood afterward: Is it stored or destroyed? The railroad workers are still waiting to find out; their test called for only two blood samples. “What did they do with the other five vials?” asks Janice Avary. She wonders: Were other tests planned?
Neurobiological disorders cause hidden costs to your company in the form of lowered productivity, increased turnover and health care claims. Diagnosis and treatment of these individuals can reduce these costs and improve their quality of life.

You’re dreading the interview. Fred is on his way to the office and you still don’t know what you’re going to say. You know it’s his last chance to keep his job. Your mind massages the behaviors, one by one, that have brought him to your attention. You’re hoping for some clue to why an obviously bright, capable person would do what he does.

Fred shows flashes of brilliance. The rest of the time he’s late finishing his work or does a mediocre job. He has difficulty getting along with his co-workers. His work area is messy and his appearance is unkempt. When his supervisor discusses these problems with him, he’s astonished and defensive.

It isn’t as if Fred were your only problem employee. You still have to deal with Beth, who has used up all her sick leave and vacation time with minor complaints: headache, stomachache and back pain. Ellen’s supervisor has complained that Ellen keeps getting up to check the copier, to make sure she reset it after she used it. She may check it 15 to 20 times. Ellen also is late for work almost every day. Then there’s Jeremy, who falls asleep at meetings, and even, sometimes, at his desk. (Is he moonlighting?) What do you do about these unmotivated employees?

There are other problems to deal with, too, such as the complaints about John. His work is fine, but four different employees have expressed concern to you that he may be on drugs. They say he keeps swinging his arms at them, and sometimes yells obscenities for no apparent reason.

The truth is, all these behaviors could be caused by any one or a combination of neurobiological disorders (NBD), a quirk—usually genetic—in the chemistry or in the anatomy of the brain. They are physical disabilities that result in the inability or reduced ability of the person to control his or her behavior, movements, emotions or thoughts.

There are many disorders of this type, including autism and pervasive developmental disorders, schizophrenia, anxiety and panic disorders, but in the workplace you’re most likely to see:

1) Attention deficit disorder (ADD, or ADHD if hyperactivity is present): a difficulty in concentrating that produces multiple symptoms, sometimes including hyperactivity
2) Depression: uncontrollable sadness for no apparent reason, clinical depression) or in some people depression alternating with manic, or high-activity states (bipolar depression)
3) Obsessive-compulsive disorder (OCD): uncontrollable and recurring thoughts or behaviors relating to an unreasonable fear

4) Narcolepsy: uncontrollable sleepiness, even after what should be adequate sleep
5) Tourette syndrome (TS): uncontrollable movements or utterances, sometimes even obscenities.

There usually are additional symptoms, some of which are shared by two or more of these disorders. Some individuals have more than one disorder. This makes diagnosis difficult.

If you’re managing 500 people, it’s possible that nearly 100 of them have at least a mild form of one or more of these disorders. NBDs cost your company in increased medical benefits, absenteeism, reduced productivity and turnover. In fact, Peter Ross, executive director of the National Foundation for Depressive estimates the cost to U.S. businesses from depression alone to be between $27 billion and $35 billion each year.

Although many people who have neurobiological disorders don’t know what’s wrong with them, some do, and the new Americans with Disabilities Act (ADA) may require you to accommodate them, if necessary, so they can do their jobs, as long as it’s reasonably possible to do so. You also can’t refuse to hire them, if they can perform the “essential functions” of the job. You must hire them and accommodate them, but, undiagnosed, they’ll cost you. Does the situation sound like a Catch 22? It needn’t be one. These disorders are physical conditions that are treatable and have a high rate of successful response to treatment.

“Research in the last few years has documented the physical basis of these disorders,” says Enid Peschel, co-director, Program for Humanities in Medicine and assistant professor (adjunct) of Internal Medicine at Yale University School of Medicine. “There has been a belief that such disorders as OCD were the result of inner conflicts. Now we know that they result from a malfunction in the basal ganglia of the brain,” she adds.

Alan Zametkin, MD, psychiatrist at the National Institute of Mental Health in Bethesda, Maryland, has used positron emission tomography (PET) to study the brains of adults who have ADHD (ADD that includes hyperactivity). He has found that certain parts of the brain that control attention are underactive in persons who have ADHD as compared with normal brains. This helps explain why stimulant medications often help calm these people.

The most successful treatment available today is medication, often combined with support groups or reality-based support, such as training in coping mechanisms. That doesn’t mean these people are sedated to prevent the undesirable behavior. The various medications used for these conditions actually correct the malfunction, just as medication is used to correct an irregular heartbeat or high blood pressure. “Medication may not always be able to stop you from hallucinating, but the proper medication often can help even a person who has persistent symptoms to function adequately,” Peschel points out. (Most NBD employees you’ll see in your work force won’t have hallucinations. Although people who do, such as individuals who have depression, or even some who have schizophrenia, may be employable, thanks to medication.)
Medication produces success in varying degrees depending upon the level of severity of the disorder, the individual’s biochemistry, and other factors, including a supportive environment. Often the dosage or the choice of medication must people who have these disorders, however, can function normally, or almost normally, after appropriate medication is determined and coping mechanisms have been taught.

David E. Comings, MD, director of the Department of Medical Genetics at the City of Hope National Medical Center in Duarte, California, works with patients who have Tourette Syndrome (TS). He says TS and ADD are closely associated. Between 50% and 80% of his TS patients also have ADD. He estimates that medication in some form is effective 80% to 90% of the time.

Paul H. Wender, MD, professor of psychiatry and director of psychiatric research at the University of Utah Medical Center in Salt Lake City, says, “ADD adults who respond to medication and stay on that medication for a long time get their lives together. There’s improvement across all areas. Patients don’t become tolerant to medication. The only problem is that many of the drugs that are effective are dealable on the street; amphetamines have been known since 1937 to be effective for ADD] but Ritalin is usually prescribed,” he says.

Because these are controlled substances, doctors are very careful to document their rationale for prescribing them. People who have ADD don’t become addicted to the medication, because the biochemical reaction produced isn’t the same as that found in people who don’t have the disorder, Wender says.

Untreated, NBD adults often become addicted to other substances, however. Joan Andrews, an educational psychologist in Newport Beach, California, who specializes in children and adults who have ADD, estimates that 33% of alcoholics are ADD adults who subconsciously try to self-medicate.

According to Ross, people who have depression also often attempt to self-medicate with alcohol or drugs. Proper treatment of the disorder can prevent substance abuse in these individuals and may be essential if needed chemical dependency treatment is to be successful.

For years these conditions have been treated with various types of psychotherapy. It was believed that NBDs were caused by dysfunctional families or traumatic childhood experiences. Although this treatment sometimes may have been helpful, the basic problem usually returned. “They’re in a hole in the ground. If you throw these people a rope—psychotherapy—they climb out and they’re fine, but then they revert,” Wender says.

Although the NBD disorder itself doesn’t respond to psychotherapy, living with such problems for any length of time often creates secondary problems that make counseling in some form beneficial. Training the individual to understand his or her condition is an important part of the treatment, the same as it would be for a person recovering from a heart attack, or learning to live with diabetes. “The patient needs reality-based supportive counseling, the way you work with anyone who has any other chronic physical illness,” Peschel says. Ideally, this reality-based supportive counseling should include the family, as well.
When the family becomes involved, other family members may be discovered to have the same disability. This is because these disorders are often genetic. “If a child has ADD, most likely both parents have it in some form or other,” says Andrews, who adds that ADD is a recessive trait. (Research at the City of Hope has demonstrated this as well.)

“Usually the family can get along better after treatment. They don’t take the person’s behavior personally anymore. That helps,” says Comings.

This can be true of co-workers, as well. An employee-education program on neurobiological disorders can help you locate these people and help members of the work force understand how to help them.

Employers often can help increase both the productivity and the comfort level in their employees who have neurobiological disorders by making some minor accommodations for them. The accommodations needed vary, depending on the disorder and the individual.

Insurance is another issue. Unfortunately, most insurance plans still call these neurobiological disorders mental health problems and don’t cover them on the same level as other physical illnesses. “It would save money if NBD were covered on a par with other physical illnesses. If people aren’t treated, the illness gets worse,” Peschel says. These are physical problems, but are classified by insurance companies as mental health issues.

Peschel says that one example is Parkinson’s disease and schizophrenia. “They’re opposite sides of the same coin: Parkinson’s disease is associated with too little dopamine, and schizophrenia with an excess of dopamine, yet Parkinson’s disease is considered a physical problem (a disease) and schizophrenia a mental one,” she points out. If you have a large enough insurance pool, as do many group insurance companies providing corporate health benefits, it needn’t be very expensive to make sure these disorders are covered completely, she says.

Some insurance programs won’t cover a person at all if he or she has a pre-existing condition. Sometimes the whole family is denied coverage because one person has TS, for example.

The treatment itself can cause problems for the NBD employee. If your company has a drug-testing program, medications used to treat NBD will show up. Employees who are taking medication for a neurobiological disorder should have written statements from their doctors on file, indicating that these drugs are being used for a legitimate purpose. Also, some of these medications must be taken during working hours. The environment at work should make it comfortable for employees who have already-diagnosed neurobiological disorders to make this known.

Fred, Beth, Ellen, Jeremy and John are just five of the nearly 100 people in your work force affected by these disorders. Fred, for instance, has ADD. Attention deficit disorder. “Often people who have ADD come to me because they’re having problems with their jobs. One of the symptoms is disorganization,” Andrews says. These people often are underachievers. They work too slowly for their abilities. Their work may be brilliant one day and mediocre the next, but they’re unaware that they’re doing anything differently. This variable performance is a symptom, she says.
It’s estimated that from 3% to 10% of all children have ADHD (ADD) and
that in one-third to two-thirds of these individuals it persists into adult life—that
is, at least 1%, and as much as 6% or 7% of the total population,” says Wender.
These people are distractible and lack concentration. “If they’re workers on an oil
rig, it doesn’t matter.” Working on routine paperwork at a desk may be a different
matter. They can have volatile mood swings, a hot temper. They’re overly reactive.
Then they cool down rapidly,” he says.

“They’re impulsive, from trivial to severe. They interrupt, because they’re
afraid they’re going to forget what they wanted to say. They may buy impulsively,
quit jobs for little reason. Some may be physically hyperactive and fidgety,”
Wender adds.

“They may tell the boss where to go; then the boss tells them where to go,”
Comings says, so they may change jobs often. “They’re poor listeners. They often
know what you’re going to say before it’s out of your mouth.”

NBD adults who have achieved white-collar status may have done so because
they have developed more successful coping mechanisms or have been fortunate
enough to be blessed with high intelligence or family members who keep them on
task. “Lower-level employees may have problems different from those of white-
collar workers,” Andrews says. “They’re more likely to have problems with punct-
tuality, personal relationships, problems filling out the time card, jobs that are
routine. Many of these people do better outdoors as truck drivers or drilling-rig op-
erators. Inside they feel confined if they’re in one spot. They may have depression
or mood swings.” Often these people are very intelligent. They’re just working
much below their abilities, she adds.

“On the positive side, they often are very creative, artistic, good with their
hands and driven. They can be good employees. Some are workaholics or mildly
obsessive-compulsive,” says Comings. The difficulty is, these highly driven ADD
individuals may go off and start their own businesses. Then you’ve lost talent and
gained competition, he warns.

One odd characteristic of ADD is the way it often disappears when the person is
performing an activity he or she likes and finds challenging. Although sitting in one
place, performing a simple, routine activity for hours on end is generally difficult or
impossible for these people, some of them have no difficulty turning out a complex and
thorough report on a subject they like, according to Andrews. Of course, this effect can
be observed in most non-ADD individuals, as well. The difference is a matter of
degree. Even extreme necessity usually doesn’t help the ADD person overcome this
difficulty. In fact, adding pressure may make the activity more difficult. When ADD
is coupled with high intelligence, finding that challenge becomes an even greater
problem, especially in light of the fact that these people may be underemployed.

Fred has an I.Q. of 125. That isn’t the only statistic on him that’s high. At 40,
he’s had three marriages and 36 jobs. He’s had more traffic tickets than he can
count. Still, things could be worse. Some ADD adults end up in our correctional
system. Fred is trying to run the race with 20-pound weights around each leg. What
can you do to help him? First, refer him to a psychiatrist or psychologist who spe-
cializes in neurobiological disorders.
Approach the employee kindly, tell him or her what you’ve observed and then recommend someone who can help. Offer hope,” Wender recommends. Find a therapist who’s pharmacologically sophisticated and can separate the various disorders, because people who display the same behaviors may have entirely different problems. (See “Where To Get Help, page 95.)

Diagnosis is complicated. Although the area of dysfunction shows up on the PET scan, the specific disorder can’t be identified. ADD can be identified through a battery of psychometric tests and a lengthy history that includes the patient’s description of functioning and symptoms, and descriptions by his or her spouse or other person.

“There are something like 303 different ways ADD can appear. It’s like putting together a jigsaw puzzle,” Andrews explains. “Younger psychiatrists are aware of the proper treatment for adults who have ADD. It’s in the medical textbooks now,” she says. An educational psychologist often is good. These people have been diagnosing and treating ADD in children for years. Only in the last 10 years has it been recognized that it can extend into adulthood. The medications used are the same as those prescribed for ADD children, she adds.

If you have an employee who has been exercising heavily on a regular basis, then has to quit for some reason, and begins to have difficulty completing work assignments, there’s a possibility that person has ADD. “Exercise may be a form of self-medication,” Andrews says. Anyone who has an ADD child should consider being evaluated if he or she has of the symptoms.

Although she says she believes the ADD adult must fit into the workplace, not have the workplace adjusted for him or her, Andrews says there are ways employers can get more out of these employees.

They may need more time to finish assignments or an environment with fewer distractions, she says. Some of them actually concentrate better with a radio playing—others need silence. Things most people can block out during concentration tend to crowd in on the ADD individual and snatch away already-elusive thoughts.

Structuring their work so that they can work on one assignment at a time, perhaps continuing without a break until they finish may be helpful. (Some ADD adults may be nervous and fidgety during a break, when they have nothing to do, and then have difficulty getting back to work.) Setting deadlines for project completion works better for these individuals, who tend to be procrastinators.

Small, tedious tasks should be collected until there are a number of them and then completed all at once. A deadline is good for these, as well. A time-management class or seminar can be helpful if it’s especially aimed at the ADD population.

ADD adults often have serious short- and long-term memory problems. Reminding them of anything that’s important but routine, when possible, can save a lot of wear and tear on the employee and his or her co-workers and supervisor.

Many people find they can concentrate better on what’s going on in a meeting if they take notes, doodle or participate in some other quiet activity as they listen.
Some people participate actively in the discussion to keep their minds from wandering. Find out what specific problems the employee has and work together to find creative solutions.

One ADD businessman was able to solve his credit problem by himself, but kept making poor hiring choices because he was so impulsive that he hired anyone who walked in the door. After he made the hiring process a committee responsibility, the problem was solved, Andrews says. Most of these people can be valued workers, she adds.

Fred most likely has developed a number of coping mechanisms. Some of these may cause problems after Fred is treated for ADD. Others may make him more efficient than other, equally talented individuals. Fred has carried an extra weight around with him all his life. If you can help him to lighten that weight, you may be amazed at what he can do.

Clinical depression. That explains Fred, but what about Beth? Although her symptoms could have another cause, Beth has major depression. Any employee who exhibits a loss of energy and interest, diminished ability to enjoy life, change in sleeping or appetite, or difficulty in concentrating, should be evaluated and treated by a biologically based psychiatrist or physician, as should anyone who appears to be in a manic state, which may appear as a high energy level, an unwarranted or exaggerated belief in one's own ability, extreme irritability or impulsive behavior. (If some of these symptoms seem similar to those of ADD, it's because they are. Correct diagnosis requires expert evaluation.)

Symptoms to Watch For

Any one of these symptoms in itself doesn't mean the employee has a neurobiological disorder. If several of these symptoms are present, he or she should be referred for an evaluation. The correct diagnosis is crucial to determining effective treatment. A skilled diagnostician can rule these disorders out and the person can be referred for psychotherapy, if indicated. Years of psychotherapy will serve little purpose, however, if a neurobiological disorder is left untreated.

Behaviors

Excessive tardiness or absenteeism, poor or inconsistent performance, distractibility, temper outburst, impulsive behavior, poor peer relationships, foul language or other uncontrolled utterances, excessive sleepiness, hoarding, poor stress tolerance, messiness, unkempt appearance, substance abuse, recklessness, mood swings, extreme changes in appetite, forgetfulness frequent physical complaints, persistent sadness, chronic fatigue, loss of interest in activities, isolation, repeated checking activities, superstitious behavior.

Movements

Clumsiness, involuntary movements, physical collapse, fidgeting, muscular weakness, lethargic movement.
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**Thoughts**

Pre-sleep (hypnagogic) hallucinations, recurring thoughts about death, inability to hold a thought, uncontrolled thoughts of one thing, fuzzy thinking.

**Other Signs**

- A child or other family member diagnosed as having one of these disorders.
- Heavily chapped hands
- Skydiving, gambling, heavy exercise, coupled with behavioral, movement or thought symptoms.

**Accommodating an NBD Employee**

Mild forms of these disorders may not require an accommodation on the part of the employer, but providing them may improve performance. More severely affected employees may need greater adjustments to their and environment, especially those workers who have attention deficit disorder, obsessive-compulsive disorder, narcolepsy or Tourette syndrome combined with ADD.

The variety of manifestations are as many as the number of individuals who have these disorders. Usually the cost—if any—is small. Find out what problems your employee has and work together to find helpful accommodations. Here are some that may help some people:

- Some people work better on their feet or moving around, at least for part of the day
- Some people have difficulty coping with using the telephone. Reassign telephone duty, if appropriate
- Total quiet or radio background can help some people concentrate
- Some people work better when they have clear deadlines
- An extended lunch period and a place to nap help some
- Some people may work better at home, where they can nap as needed, concentrate without interruptions or avoid worry about venturing outside.
- Allow a person who has ADD to sit in the front row during large meetings. Fellow workers in an audience may be a distraction
- Teach the person to collect routine tasks and then perform all at once at a pre-arranged time
- Provide a forum for the person to share his or her problems with co-workers
- Provide a person the employee can consult as needed to discuss problems as they occur.