

When diseases have a bad name, change is hard

October 2 2013, by Kerry Sheridan

Some diseases just have a bad name. But even when their commonly known labels glorify Nazi doctors or slander certain ethnic groups, old habits are hard to change, experts say.

Medical conditions, viruses and even personality quirks have long been named after places, famous athletes, pioneering [doctors](#) and literary giants.

The H1N1 influenza that sparked a worldwide pandemic in 2009 was initially called Mexican swine flu, while Pickwickian syndrome is another name for obesity hypoventilation syndrome, based on a fat character in a Charles Dickens novel.

The most recent affliction to make headlines is Middle East Respiratory Syndrome Coronavirus, or MERS-CoV, which has killed 58 of the 130 people infected since 2012.

The illness has been found in Saudi Arabia, Tunisia, Jordan, Qatar, and the United Arab Emirates.

Its name initially referred to Saudi Arabia, because an Egyptian scientist first identified it in a Saudi patient.

But, according to Ron Fouchier, a leading scientist at Erasmus Medical Center in the Netherlands where the analysis was done, Saudi officials "were not pleased."

"We then renamed the virus isolate HCoV-EMC for human coronavirus Erasmus MC, to take away any sensitivities," he told AFP.

But Fouchier said Saudi leaders were not pleased by the new name either, so he and other investigators convened, discussed and agreed unanimously on a new name: MERS-CoV.

The World Health Organization approved the name in May, but added: "WHO generally prefers that virus [names](#) do not refer to the region or place of the initial detection."

NO CENTRAL AUTHORITY

With no central regulatory body for names, diseases and conditions can end up with multiple or contentious labels.

"Where there's disagreement, it can get messy," said Stephanie Morrison, an expert with the Genetics Home Reference at the US National Library of Medicine.

Some inappropriate names have quickly disappeared.

HIV/AIDS was once referred to as 4-H disease, referring to Haitians, homosexuals, hemophiliacs and heroin. Another name that was introduced in 1982 but soon vanished was GRID, for Gay-related immunodeficiency.

No longer are diseases regularly named after their discoverers, but many persist, like Alzheimer's disease (after a German psychiatrist) and Tourette's syndrome (after a French neurologist).

Naming conditions after geographic places has created memorable descriptors—but which tend to offend.

The naming of a new drug-resistant superbug in 2009 after New Delhi sparked outcry in India, where medical experts and parliamentarians said the name cast the city as a dirty place.

The enzyme was named New Delhi metallo-lactamase-1, or NDM-1, and its related gene blaNDM-1, after it was found in an Indian man who had settled in Sweden but became ill on a visit to India in 2007.

The superbug has since been found around the world, noted Ajai Singh, a doctor in Mumbai who has likened the label to "name calling."

He proposed creating an international commission for creating medical monikers—but it has not happened.

And "the name NDM-1 continues to be widely used. Habits die hard, even with scientists," he told AFP in an email.

NAZI NAMES LINGER

Even when the scientific community agrees that a name should change, as in the case of a rare neurological defect named Hallervorden-Spatz disease after the Nazi doctors who first described it, the process can take decades.

"I don't want the disease to have anything to do with them," said Patty Wood, whose daughter Kimbi, now 27, was diagnosed at age three when she gradually lost the ability to walk and talk.

When Wood learned that Julius Hallervorden and his boss Hugo Spatz did their research on the brains of exterminated children, she changed the name of the advocacy group she founded to the Neurodegeneration with Brain Iron Accumulation (NBIA) Disorders Association and urged doctors to change their habits as well.

That was 10 years ago.

Yet "there are still some doctors outside of the United States that give a diagnosis of Hallervorden-Spatz," said Wood, mentioning families in South America and India.

A study out last year said use of the term Hallervorden-Spatz has declined by about half since the 1990s, which researcher Michael Shevell of McGill University described as "an unconscious collective decision by the neurologic community to 'do the right thing.'"

SHAKESPEARE ANYONE?

Other names spring from less controversial sources. For instance, Irish doctors recently suggested naming the death-bed habit of grasping at bedclothes as "Henry V sign."

The description is seen in Shakespeare's Henry V, in which Mistress Quickly describes the nearing death of Falstaff, saying she saw him "fumble with the sheets and play with flowers and smile upon his fingers' ends."

Fergus Shanahan, chair of the department of medicine at University College Cork, said the name worked "because most people know Shakespeare to some degree."

"It is a kind of shorthand description for something that is quite complex but also very common."

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