

Helping kids who developed sleep disorder after controversial vaccination

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Children and adolescents who developed narcolepsy following the mass vaccinations during the global outbreak of swine flu can now expect better support from Norway's public health services.

As of March 2012, 39 new registered cases of narcolepsy have been diagnosed among people aged 4-19 who were vaccinated against swine flu, according to figures from the Norwegian Medicines Agency.

In the same period only four non-vaccinated children were diagnosed with the chronic sleeping disorder.

A nationwide project is being set up to help young people who have developed narcolepsy, including those who contracted the disease in connection with the H1N1 pandemic and taking the vaccine Pandemrix.

This vaccine is no longer being used in Norway.

The vaccination program caused a heated debate, and only half of the population ended up taking the vaccine.

Ensuring individual help

The patients with narcolepsy will be followed up locally by the primary health services in their communities. Expertise and collaboration in diagnostics and treatment will be implemented in several parts of the country.

The follow-ups and treatment will be individually adapted to levels of severity on a case-by-case basis.

“The public health authorities want to establish a national project that ensures proper follow-ups for these young patients,” says Division Director Cecilie Daae at the Norwegian Directorate of Health. “We certainly need a solid system for treatment and follow-ups.”

The new project will largely focus on improving information, advice and research about the disorder. A number of health agencies and national competence units will be involved in the project.

Special situation after pandemic

“We have a special situation with many children and teens in Norway and other countries developing narcolepsy following the swine flu pandemic,” says Solveig Ervik, who heads the national services for rare diseases.

The National Competence Centre for AD/HD, Tourettes Syndrome and Narcolepsy at the Oslo University Hospital is one of the units that will be working with the children.

“This competence centre has already done much for these patients and it will get engaged in additional

initiatives to spread information and give advice,” says Ervik.

“The young people, their parents, teachers and others need better information about how to live as well as possible with this disorder,” she says.

“For example, educators need to know how to adapt their teaching.”

Vaccine caused sleep disorder

SOVno, a competence centre for sleeping disorders at Haukeland University Hospital in Bergen, will also contribute in the new efforts.

“We are fully behind this initiative,” says Professor Bjørn Bjorvatn.

“Narcolepsy is a rare and serious sleeping disorder. A clear increase among children and people under the age of 18 has appeared after the vaccinations against swine flu in Norway, Sweden and Finland. We can say with a relatively high degree of certainty that this has been a triggering factor for the disorder.”

A new registry for narcolepsy

The Norwegian Directorate of Health wants to establish a high-quality voluntary registry of narcolepsy patients. The authorities hope to enrol as many as possible of the young patients in the registry.

“A special narcolepsy registry is essential for collecting information about such things as the effects and safety of treatment methods,” says Daae.

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May 3, 2012 - 07:00

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