



EDITION: U.S.

Search News & Quotes

Anfi

Home

Business

Markets

World

Politics

Tech

Opinion

Breakingviews

Money

Life

Pictures

Video

HAPPENING NOW: Live coverage of World Economic Forum in Davos

ARTICLE

COMMENTS (16)

SLIDESHOW

INTERACTIVE

Follow Reuters

Facebook

Twitter

RSS

YouTube

RECOMMENDED VIDEO

Insight: Evidence grows for narcolepsy link to GSK swine flu shot



Tweet

Share

Share this

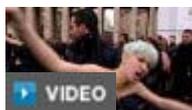
29

Email

Print

Related News

[Flu-conomics: The next pandemic could](#)



[Topless protest against Vatican's anti-gay stance...](#)



[NYC and Mexico commuters caught in subway with no...](#) [?]

READ

[North Korea to target U.S. with nuclear, rocket tests](#)

4:31am EST

[Beyonce lets others do talking on lip-synch drama](#)

23 Jan 2013

[Apple's iPhone disappointment fans doubt on growth](#)



6:36am EST

[Ryan blames Republican election loss on poor communication, turnout](#)

23 Jan 2013

[U.S. to lift ban on women in front-line combat jobs](#)

23 Jan 2013

DISCUSSED

159

[Clinton defends her handling of Benghazi attack in testimony](#)

By Kate Kelland, Health and Science Correspondent

STOCKHOLM | Tue Jan 22, 2013 7:26am EST

(Reuters) - Emelie Olsson is plagued by hallucinations and nightmares. When she wakes up, she's often paralyzed, unable to breathe properly or call for help. During the day she can barely stay awake, and often misses school or having fun with friends. She is only 14, but at times she has wondered if her life is worth living.

Emelie is one of around 800 children in Sweden and elsewhere in Europe who developed narcolepsy, an incurable sleep disorder, after being immunized with the Pandemrix H1N1 swine flu vaccine made by British drugmaker GlaxoSmithKline in 2009.

Finland, Norway, Ireland and [France](#) have seen spikes in narcolepsy cases, too, and people familiar with the results of a soon-to-be-published study in Britain have told Reuters it will show a similar pattern in children there.

Their fate, coping with an illness that all but destroys normal life, is developing into what the health official who coordinated Sweden's vaccination campaign calls a "medical tragedy" that will demand rising scientific and medical attention.

Europe's drugs regulator has ruled Pandemrix should no longer be used in people aged under 20. The chief medical officer at GSK's vaccines division, Norman Begg, says his firm views the issue extremely seriously and is

[trigger global recession](#)

Mon, Jan 21 2013

[RPT-INSIGHT-U.S. government investment gives flu vaccines a shot in the arm](#)

Sat, Jan 19 2013

[Flu in U.S. still widespread, but starting to ease, CDC says](#)

Fri, Jan 18 2013

[Flu vaccine not linked to fetal death](#)

Wed, Jan 16 2013

[Vaccine timetable for children is safe, experts say](#)

Wed, Jan 16 2013

Analysis & Opinion

[Flu epidemic exposes U.S. risk management flaws](#)

[How to improve vaccination](#)

Related Topics

[Health »](#)

[Investing and Taxes Simplified »](#)

149 [Obama seeks "fuller understanding" of what happened in Algeria siege](#)

128 [With array of challenges, Obama kicks off second term at public inauguration](#)

PICTURES



Reuters Photojournalism

Our day's top images, in-depth photo essays and offbeat slices of life. See the best of Reuters photography.

[See more](#) | [Photo caption](#)



India's women defend themselves

Women in India take steps to ensure their security in the aftermath of the death of a medical student who was gang raped on a bus. [Slideshow](#)

[Slideshow](#)

"absolutely committed to getting to the bottom of this", but adds there is not yet enough data or evidence to suggest a causal link.

Others - including Emmanuel Mignot, one of the world's leading experts on narcolepsy, who is being funded by GSK to investigate further - agree more research is needed but say the evidence is already clearly pointing in one direction.

"There's no doubt in my mind whatsoever that Pandemrix increased the occurrence of narcolepsy onset in children in some countries - and probably in most countries," says Mignot, a specialist in the sleep disorder at Stanford University in the United States.

30 MILLION RECEIVED PANDEMRIX

In total, the GSK shot was given to more than 30 million people in 47 countries during the 2009-2010 H1N1 swine flu pandemic. Because it contains an adjuvant, or booster, it was not used in the United States because drug regulators there are wary of adjuvanted vaccines.

GSK says 795 people across Europe have reported developing narcolepsy since the vaccine's use began in 2009.

Questions about how the narcolepsy cases are linked to Pandemrix, what the triggers and biological mechanisms might have been, and whether there might be a genetic susceptibility are currently the subject of deep scientific investigation.

But experts on all sides are wary. Rare adverse reactions can swiftly develop into "vaccine scares" that spiral out of proportion and cast what one of Europe's top flu experts calls a "long shadow" over public confidence in vaccines that control potential killers like measles and polio.

"No-one wants to be the next Wakefield," said Mignot, referring to the now discredited British doctor Andrew Wakefield who sparked a decades-long backlash against the measles, mumps and rubella (MMR) shot with false claims of links to autism.

Related Interactive



Narcolepsy diagnosis in Sweden and Finland



Syrian rebels in Damascus

Rare photos of rebels operating in the Syrian capital from Reuters photographer Goran Tomasevic.

[Slideshow](#)

SPONSORED LINKS

Ads by Marchex

With the narcolepsy studies, there is no suggestion that the findings are the work of one rogue doctor.

Independent teams of scientists have published peer-reviewed studies from Sweden, Finland and [Ireland](#) showing the risk of developing narcolepsy after the 2009-2010 immunization campaign was between seven and 13 times higher for children who had Pandemrix than for their unvaccinated peers.

"We really do want to get to the bottom of this. It's not in anyone's interests if there is a safety issue that needs to be addressed," said GSK's Begg.

LIFE CHANGED

Emelie's parents, Charles and Marie Olsson, say she was a top student who loved playing the piano, taking tennis lessons, creating art and having fun with friends. But her life started to change in early 2010, a few months after she had Pandemrix. In the spring of 2010, they noticed she was often tired, needing to sleep when she came home from school.

But it wasn't until May, when she began collapsing at school, that it became clear something serious was happening.

As well as the life-limiting bouts of daytime sleepiness, narcolepsy brings nightmares, hallucinations, sleep paralysis and episodes of cataplexy - when strong emotions trigger a sudden and dramatic loss of muscle strength.

In Emelie's case, having fun is the emotional trigger. "I can't laugh or joke about with my friends any more, because when I do I get cataplexies and collapse," she said in an interview at her home in the Swedish capital.

Narcolepsy is estimated to affect between 200 and 500 people per million and is a lifelong condition. It has no known cure and scientists don't really know what causes it. But they do know patients have a deficit of a brain neurotransmitter called orexin, also known as hypocretin, which regulates wakefulness.

Research has found that some people are born with a variant in a gene known as HLA that means they have low hypocretin, making them more susceptible to narcolepsy. Around 25 percent of Europeans are thought to have this genetic vulnerability.

When results of Emelie's hypocretin test came back in November last year, it showed she had 15 percent of the normal amount, typical of heavy narcolepsy with cataplexy.

The seriousness of her strange new illness has forced her to contemplate life far more than many other young teens: "In the beginning I didn't really want to live any more, but now I have learned to handle things better," she said.

TRIGGERS?

Scientists investigating these cases are looking in detail at Pandemrix's adjuvant, called AS03, for clues.

Some suggest AS03, or maybe its boosting effect, or even the H1N1 flu itself, may have triggered the onset of narcolepsy in those who have the susceptible HLA gene variant.

Angus Nicoll, a flu expert at the European Centre for Disease Prevention and Control (ECDC), says genes may well play a part, but don't tell the whole story.

"Yes, there's a genetic predisposition to this condition, but that alone cannot explain these cases," he said. "There was also something to do with receiving this specific vaccination. Whether it was the vaccine plus the genetic disposition alone or a third factor as well - like another infection - we simply do not know yet."

GSK is funding a study in Canada, where its adjuvanted vaccine Arepanrix, similar to Pandemrix, was used during the 2009-2010 pandemic. The study won't be completed until 2014, and some experts fear it may not shed much light since the vaccines were similar but not precisely the same.

It all leaves this investigation with far more questions than answers, and a lot more research ahead.

WAS IT WORTH IT?

In his glass-topped office building overlooking the Maria Magdalena church in Stockholm, Goran Stiernstedt, a doctor turned public health official, has spent many difficult hours going over what happened in his country during the swine flu pandemic, wondering if things should have been different.

"The big question is was it worth it? And retrospectively I have to say it was not," he told Reuters in an interview.

Being a wealthy country, Sweden was at the front of the queue for pandemic vaccines. It got Pandemrix from GSK almost as soon as it was available, and a nationwide campaign got uptake of the vaccine to 59 percent, meaning around 5 million people got the shot.

Stiernstedt, director for health and social care at the Swedish Association of Local Authorities and Regions, helped coordinate the vaccination campaign across Sweden's 21 regions.

The World Health Organisation (WHO) says the 2009-2010 pandemic killed 18,500 people, although a study last year said that total might be up to 15 times higher.

While estimates vary, Stiernstedt says Sweden's mass vaccination saved between 30 and 60 people from swine flu death. Yet since the pandemic ended, more than 200 cases of narcolepsy have been reported in Sweden.

With hindsight, this risk-benefit balance is unacceptable. "This is a medical tragedy," he said. "Hundreds of young people have had their lives almost destroyed."

PANDEMICS ARE EMERGENCIES

Yet the problem with risk-benefit analyses is that they often look radically different when the world is facing a pandemic with the potential to wipe out millions than they do when it has emerged relatively unscathed from one, like H1N1, which turned out to be much milder than first feared.

David Salisbury, the British government's director of immunization, says "therein lies the risk, and the difficulty, of working in public health" when a viral emergency hits.

"In the event of a severe pandemic, the risk of death is far higher than the risk of narcolepsy," he told Reuters. "If we spent longer developing and testing the vaccine on very large numbers of people and waited to see whether any of them developed narcolepsy, much of the population might be dead."

Pandemrix was authorized by European drug regulators using a so-called "mock-up procedure" that allows a vaccine to be authorized ahead of a possible pandemic using another flu strain. In Pandemrix's case, the substitute was H5N1 bird flu.

When the WHO declared a pandemic, GSK replaced the mock-up's strain with the pandemic-causing H1N1 strain to form Pandemrix.

GSK says the final H1N1 version was tested in trials involving around 3,600 patients, including children, adolescents, adults and the elderly, before it was rolled out.

The ECDC's Nicoll says early warning systems that give a more accurate analysis of a flu strain's threat are the best way to minimize risks of this kind of tragedy happening in future.

Salisbury agrees, and says progress towards a universal flu vaccine - one that wouldn't need last-minute changes made when a new strain emerged - would cut risks further.

"Ideally, we would have a better vaccine that would work against all strains of influenza and we wouldn't need to worry about this ever again," he said. "But that's a long way off."

With scientists facing years of investigation and research, Emelie just wants to make the best of her life.

She reluctantly accepts that to do so, she needs a cocktail of drugs to try to control the narcolepsy symptoms. The stimulant Ritalin and the sleeping pill Sobril are prescribed for Emelie's daytime sleepiness and night terrors. Then there's Prozac to try to stabilize her and limit her cataplexies.

"That's one of the things that makes me feel most uncomfortable," she explains. "Before I got this condition I didn't take any pills, and now I have to take lots - maybe for the rest of my life. It's not good to take so many medicines, especially when you know they have side effects."

(This story has been corrected to insert full name in first paragraph)

(Reporting by Kate Kelland; Editing by Will Waterman)

HEALTH INVESTING AND TAXES SIMPLIFIED

Related Quotes and News

COMPANY	PRICE	RELATED NEWS
GlaxoSmithKline PLC GSK.L	1,424.00p +9.00 +0.64%	BRIEF-GlaxoSmithKline makes submission to U.S. FDA for diabetes drug BRIEF-GSK, Theravance submit regulatory application in EU for UMEC/VI More GSK.L News »

Tweet this

Link this

Share this

Digg this

Email

Reprints

More From Reuters

[Armstrong's mask slips as he reveals toll on family](#) | Jan. 19

[The Swiss turn on the super-rich](#) | Jan. 21

[RPT-INSIGHT-U.S. government investment gives flu vaccines a...](#) | Jan. 19

From Around the Web

[iPhone 6 'about to enter production, packs 4.8" screen'](#) (uSwitch)

[MDLinx Survey: 22.6 Percent Of US Docs Report Most Patients...](#) (dlvr.it)

[The Underwear that's Changing the World](#) (Goodnet)

Iran hangs two men for attack posted on YouTube | Jan. 20

Illinois father and two sons freeze to death during hike | Jan. 14

Why Microsoft is cutting back in Germany
(Global Connections)

Skiing atheist joins lawsuit to remove Whitefish Jesus... *(Missoulian)*

[?]

Videos From Reuters



Mission to Mali (1:19)



French blast rebels out of key Malian town (1:26)



French planes prepare to leave for Mali (0:53)

From Around the Web



Why China means a suitcase full of cash *(Global Connections)*



5 Foods You Can Eat To Prevent Heart Disease
(Whole Women)



Another Reason to Stop Using Credit Cards: Checkout Fees *(Rapidtmp)*

[?]

Add your comment

Post to Facebook

Zurück

Anfrage senden

We welcome comments that advance the story through relevant opinion, anecdotes, links and data. If you see a comment that you believe is irrelevant or inappropriate, you can flag it to our editors by using the report abuse links. Views expressed in the comments do not represent those of Reuters. For more information on our comment policy, see <http://blogs.reuters.com/fulldisclosure/2010/09/27/toward-a-more-thoughtful-conversation-on-stories/>

Comments (16)**OrSpeeder** wrote:<https://www.youtube.com/watch?v=tqgEMxmadtk>Jan 22, 2013 6:44am EST -- [Report as abuse](#)**americanguy** wrote:

I wonder how many people will actually get past the headline and see this does not affect the US, and they are still not sure what caused this?

About 40,000 people die in the US each year from the flu, 100 or so are children.

I had the flu about 5 years ago because I did not get the shots, I was sick as a dog. I will take my chances with the flu shots now.

Jan 22, 2013 7:28am EST -- [Report as abuse](#)

ThermoNuke wrote:

It's a total joke. The other day they cleared pregnant women to take the flu shot. They think you're an idiot!

Jan 22, 2013 9:19am EST -- [Report as abuse](#)

[See All Comments »](#)

[Add Your Comment](#)

ADS BY MARCHEX

[Buy a Link Now](#)

China leaps ahead as Europe ambles forward

LONDON - Growth in Chinese manufacturing accelerated to a two year high this month and a buoyant Germany took the euro zone economy a step closer to recovery, business surveys showed on Thursday.

[CONTINUE READING](#)

TOP NEWS



Smooth sailing seen ahead for Kerry as State Department pick

WASHINGTON - At least one of President Barack Obama's national security picks is likely to win approval easily from the U.S. Senate: his nominee for Secretary of State, John Kerry, whose confirmation hearing will be conducted by a committee he has led for four years.

[Red flags revealed in filings of firm linked to Caterpillar fraud](#)

[Mitsubishi recalls 14,700 electric cars globally over brakes](#)

[» More Top News](#)

TOP VIDEOS



PMIs: France flounders as Germany booms

[DAVOS 2013: ECB needs to be more like the BOJ](#)

[» More Top Videos](#)

MARKETS

US Indices

DOW
67.12
13,779.33
+0.49%

NASDAQ
10.49
3,153.67
+0.33%

S&P 500
2.25
1,494.81
+0.15%

TR US INDEX

MOST POPULAR

[North Korea to target U.S. with nuclear, rocket tests](#)

[Beyonce lets others do talking on lip-synch drama](#)

[Ryan blames Republican election loss on poor communication, turnout](#)

[Apple's iPhone disappointment fans doubt on growth](#) |  VIDEO

[Clinton forcefully defends handling of Benghazi attack](#) |  VIDEO

[U.S. to lift ban on women in front-line combat jobs](#)

ANALYSIS & OPINION



The Oscars: Reflections of America

By Nicholas Wapshott
By nominating "Lincoln," "Argo" and "Zero Dark Thirty," Academy members are considering three distinctly different views of how Americans see themselves and their place in the world. [Commentary](#)

[Wapshott: Do personal guns defend liberty?](#)

» [More Analysis & Opinion](#)

TODAY IN PICTURES



Editor's Choice

Our best photos from the last 24 hours.

[View Slideshow](#)

0.14

135.71
+0.10%

Int'l Indices

NIKKEI
10,620.87

HANG SENG
23,598.90

» [Markets](#)

EDITION: U.S.

[Back to top](#)

Reuters.com

[Business](#) | [Markets](#) | [World](#) | [Politics](#) | [Technology](#) | [Opinion](#) | [Money](#) | [Pictures](#) | [Videos](#) | [Site Index](#)

Legal

[Bankruptcy Law](#) | [California Legal](#) | [New York Legal](#) | [Securities Law](#)

Support & Contact

[Support](#) | [Corrections](#)

Connect with Reuters

[Twitter](#) | [Facebook](#) | [LinkedIn](#) | [RSS](#) | [Podcast](#) | [Newsletters](#) | [Mobile](#)

About

[Privacy Policy](#) | [Terms of Use](#) | [Advertise With Us](#) |  AdChoices | [Copyright](#)

Thomson Reuters is the world's leading source of intelligent information for businesses and professionals.

[Thomsonreuters.com](#)

Our Flagship financial information platform incorporating Reuters Insider

An ultra-low latency infrastructure for electronic trading and data distribution

A connected approach to governance, risk and compliance

Our next generation legal research platform

Our global tax workstation

[About Thomson Reuters](#)

[Investor Relations](#)

[Careers](#)

[Contact Us](#)

Thomson Reuters is the world's largest international multimedia news agency, providing investing news, world news, business news, technology news, headline news, small business news, news alerts, personal finance, stock market, and mutual funds information available on Reuters.com, video, mobile, and interactive television platforms. Thomson Reuters journalists are subject to an Editorial Handbook which requires fair presentation and disclosure of relevant interests.

NYSE and AMEX quotes delayed by at least 20 minutes. Nasdaq delayed by at least 15 minutes. For a complete list of exchanges and delays, please click [here](#).