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August 2nd 2022

To whom it may concern:

This letter is in support of Justine Bennet recognition of her disease status as a post vaccination case of type 1 narcolepsy. Justine Bennett is a 30 Y woman with hx of panic disorder, intermittent asthma, typical narcolepsy type 1 with cataplexy (MSL 0.4 min 5 SOREM on MSLT at outside facility) who I last saw 11/12/2021. I have been treating several hundreds of patients with narcolepsy type 1 and helped codify and improve therapy for patients. Narcolepsy is a life-long disabling disorder which can at best be alleviated but never reversed, as it is due to the loss of ~20,000 hypocretin/orexin neurons and this is irreversible.

Professor at Stanford, I have been the director of the Stanford Center for Narcolepsy, a center dedicated to understanding the cause of the disease and improving the life of these patients since 1989. I am mostly known for having found the cause of Type 1 Narcolepsy, an autoimmune mediated loss of approximately 20,000 neurons in the brain synthetizing the peptide hypocretin, also called orexin. In recognition of my work, I'm a member of both the US National Academies of Sciences and Medicine.

We later have shown that the autoimmune process destroying orexin neurons is triggered by the flu, and, although we don't understand yet exactly why, the "swine flu" H1N1 Pandemrix adjuvanted vaccine used in Europe was an unusually strong trigger, stronger than the natural flu, explaining why many cases occurred following its administration in Europe. Although it is unclear if other (non adjuvanted) vaccinations such as those used in the US and containing the 2009 H1N1 strain r increase risk, it is reasonable considering the demonstrated association with both H1N1 infections and at least one vaccination type. At minimum, it is mechanistically likely H1N1 vaccinations of any type could contribute to triggering disease.

She provided us with her flu vaccination history, which is confusing (attached is what she provided). A first flu vaccination was performed at the Contra Costa County Health services Department October 17th 2019 using an unspecified quadrivalent vaccine "preservative free" (CVX150). Unfortunately, there is no additional information, so it is uncertain what type of strain this contained; most likely based on the date the vaccine would likely have contained the old H1N1 pre 2009 pandemic strain, the H3N2, and two influenza B.

In Nov 30th 2010, she also received lot UH214AB quadrivalent, which for sure would contain pandemic 2009H1N1. However I have two different version of the record, one that says influenza split (including surface antigen)-retired code CVX=15, from Sanofi_pasteur and another same date that says FluLaval multidose with preservative quadrivalent (CVX158) from Sanofi_pasteur. Flulaval was manufactured by GSK in St Foye, Canada, not Sanofi Pasteur, but I am not sure maybe it was distributed by Sanofi_pasteur at this site thus the label. Of note, I

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was unable to find any information on the lot number through the internet. In the past this info was available, but now it seems very hard to find.

She reports that her symptoms appeared in 2010. Specifically, she started to experience sleepiness and knee buckling in the setting of sensations of love for her new born baby she attributes to cataplexy. The first documented report in her medical file of cataplexy and tiredness is during her 2019 pregnancy where notes document fatique and a ~3 yrs h/o diffuse weakness with any extreme emotions (laughing and anger) that had been getting more frequent (Dr. Nguyen, Michael H, MD, 05/09/2019 Antioch health center family medicine). A PSG MSLT subsequently confirmed the diagnosis in the context of worsening cataplexy 20-30x per day, hypersomnolence, and sleep paralysis.

I personally interviewed Justine and can attest to the following: 1) She has a typical case of type 1 narcolepsy, her symptoms are classic and there is no doubt about her diagnosis. 2) The temporal link with vaccination is within what has been commonly reported. 3). There has been a substantial delay in diagnosis. 4) Her sleep study results, MSL 0.4 min 5 SOREM on MSLT performed at outside facility are typical of narcolepsy. 5) Narcolepsy has dramatically impaired her life, and her life prospects. 6) She has been struggeling to find an active treatment and her symptoms are still not well controlled.

After speaking with her, it is clear that the disease has had a huge impact on her life and life prospects. She has been struggling to be diagnosed, and until now has not found the right treatment to control her symptoms. She continues to endorse cataplexy which is disruptive to her activities of daily living, ability to hold a job, maintain relationships and most importantly to have a stable and satisfactory quality of life. This has also been impacting her underlying mood and anxiety disorder.

Below are a few scientific papers documenting the association with the flu, vaccination (a 2019 consensus report from epidemiologists and public helath specialists), and other documenting the psychosocial effects of the disease.

Don't hesitate to contacte me if you need more information.
Sincerely,



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References

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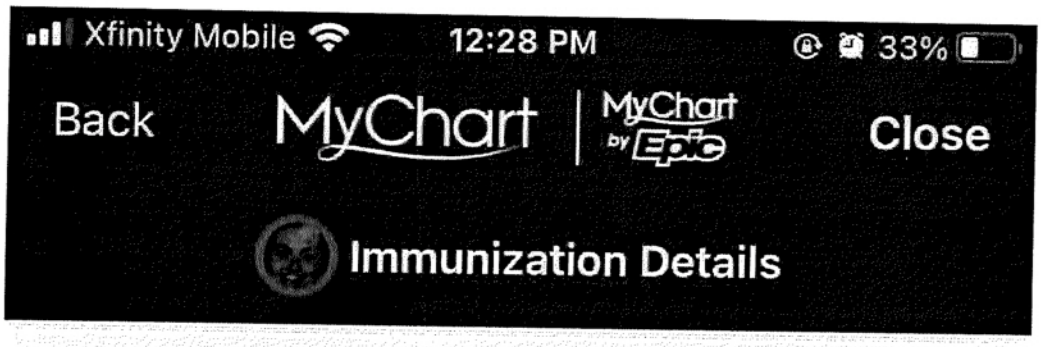
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FLU (fluLAVAL MULTI-DOSE) WITH Preservative quadrivalent (CVX=158)

This is a list of doses that your clinic has on file for you.

Administered on Nov 30, 2010

Manufacturer: Aventis Pasteur

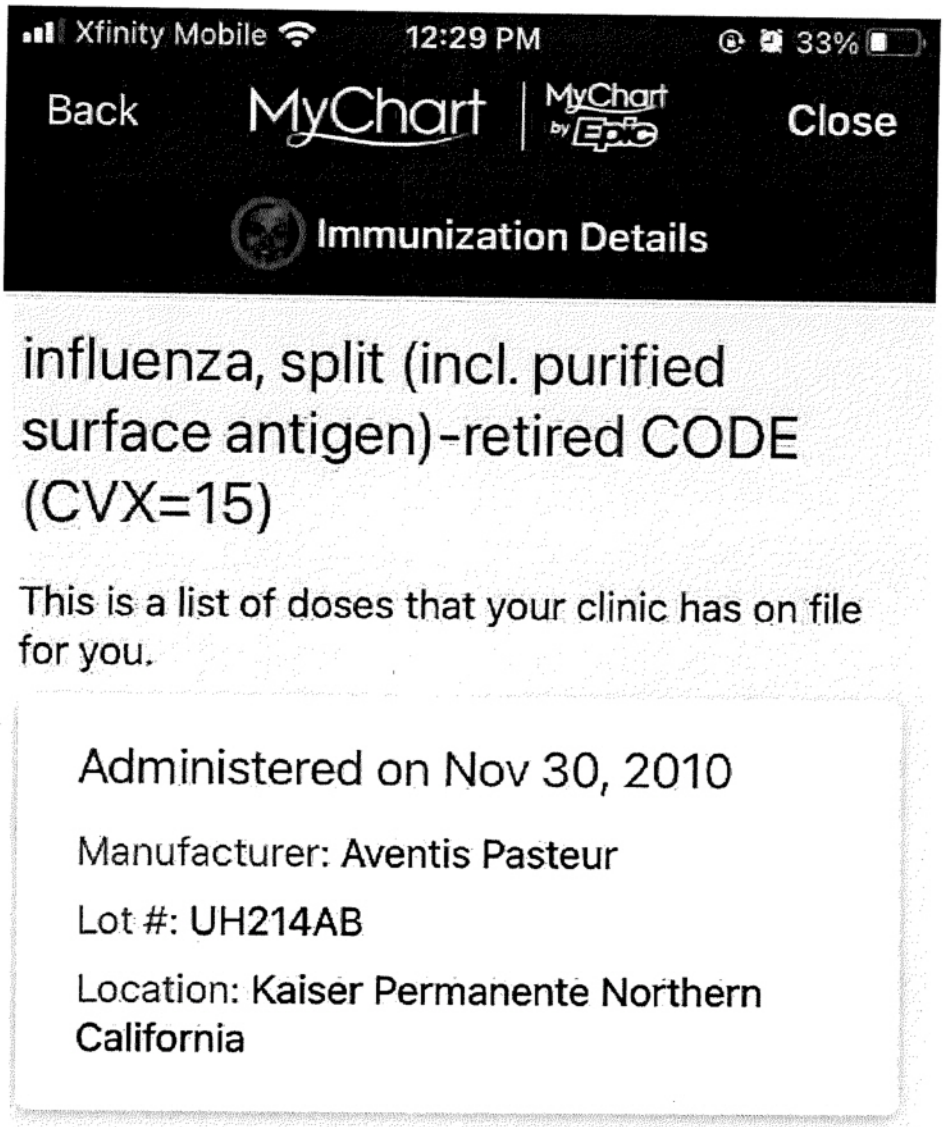
Lot #: UH214AB

Location: Kaiser Permanente Northern California

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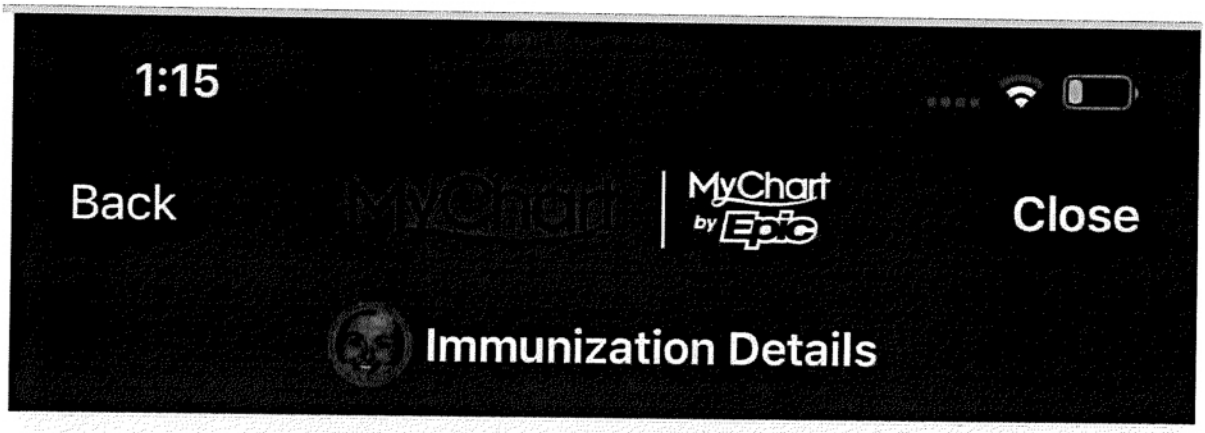
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influenza, injectable, quadrivalent, preservative free (CVX=150)

This is a list of doses that your clinic has on file for you.

Administered on Oct 17, 2019
Location: Contra Costa County Health Services Department

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