

Diary of symptoms and medical visits kept by Anja – Natasja's mother

Natasja received Gardasil 02-05-2011, 04-08-2011 and 05-12-2011

01-11-2011 Went to doctor after 2nd vaccine. Intolerable headache, tunnel vision, short-term loss of peripheral vision.

19-01-2012 After 3rd vaccine. Very sore throat.

02-02-2012 Bad flu , cannot eat, a lot of pain throughout the body, very ill for 14 days .

01-03-2012 Backache.

02-11-2012 Abdominal pain , diarrhoea, signs of cystitis.

06-11-2012 Continued intense abdominal pain.

23/12/2012 Intense back pain.

02/01/2013 Influenza for about 8 days and backache.

01-02-2013 Still has pain in back (since 23/12/2011). Worsening of headache , sore neck and shoulders.

11-02-2013 Long-term back pain, neck and shoulders, many days away from school.

02-03-2013 Hospitalised. Pain in back, neck, sensory disturbance on right side of face and down right arm. Blurred vision, severe headache .

05-03-2013 Lumbar puncture. Increased spinal pressure of 24 mm.

Discharged.

Diagnosis: neurological disorder and borrelia.

10-03-2013 Very poorly. Contacted children's ward. Continuous headaches, and disorders of the hand / arm. Pain in knees, tired, vomits.

11-03-2013 Hospitalised. Severe headache , nausea, tingling in right hand. No effect of Diclofenac and aspirin.

14-03-2013 Severe pain in lower left side of abdomen. Physiotherapy: Very difficult and pain when back is touched.

15-03-2013 Physiotherapy : Managed 300 meters on treadmill, legs collapsed and shook. Discharged from hospital.

Heart palpitations, neck lock feeling , extreme tension in head, backache, vomiting.

18-03-2013 Severe headache. Had to come home from dentist because of vomiting.

20-03-2013 Severe headache. Has had loose stools for a long time. Diamox commenced for pressure in head.

22-03-2013 Physiotherapy. Intense pain when upper back is palpated. Concentration difficulties.

30-03-2013/31-03-2013 Collapsed in kitchen. Hospitalised. Severe headache , dizziness, severe pain in the knees, cannot stand or walk , cold sweats, freezing.

31-03-2013 Discharged. Diagnosis: severe pain and benign intracranial increased pressure.

4-04-2013 Still much pain in knee and head, can hardly stand it anymore.

08-08-2013 Intense swelling of knee, much pain and redness.

09-04-2013 Diamox discontinued as no effect on pressure in head.

10-04-2013 Rheumatologist. Has had bluish shadows under eyes for two months.

Ulcers/thrush in oral mucosa. Still pressure headache . No appetite .

18-04-2013 Rash on upper body, front and back. Small lumps, sores. Dry itchy skin. Dark red and warm.

02-05-2013 Pain in knee is now also in legs, can barely drag herself upstairs.

04-05-2013 Assessed that her pain is more rheumatological than neurological .

16-05-2013 Meeting with the department and doctors. Training program advised.

04-06-2013 Still has headache. Very dark rings under the eyes.

11-06-2013 Stomach cramps, very loose bowels. Dicoflor recommended.

20-06-2013 Extreme redness, warm swollen knees. Joint pain. Still loose bowels. Dicoflor not effective.

25-06-2013 Loose stools many times daily, severe headache at night.

26-06-2013 Hospitalised. Intense headache, burning and stinging in knees, swollen with pustules. Very swollen tonsils. Still diarrhoea, very thirsty.

27-06-2013 Discharged. Still joint and knee pain, headache. Given crutches.

02-07-2013 Applied for braces for knees.

03-07-2013 Contacted department but was told that there was nothing that could be done about the diarrhoea and that it did not matter. Feels hungry all the time, was advised to drink and not eat and to apply an ointment to her sore anus.

18-07-2013 Examined by hormone specialist because of size and height.

22-08-2013 Hospitalised. Throbbing headache on the left side, vomiting. Aspirin, Ibuprofen and Maxalt do not help.

Tender in abdomen below the navel towards the right side. Pain in neck and shoulders.

23-08-2013 Headache, nausea, restless. Hot, sweating.

Discharged from hospital, with diagnosis Cephalalgia, for continued treatment at home for functional disorders. Natasja has pain in her soul.

29-08-2013 Natasja cried because of headache and sleeplessness.

14-09-2013 Very tired, went to birthday party but couldn't eat. Headache. Had to come home.

15-09-2013 Natasja and a girlfriend slept together, they got up, had breakfast, but in early afternoon she was tired, dizzy, nauseous, severe headache. I drove her friend home, Natasja went to bed.

16-09-2013 Natasja was due to go to a special school, I drove her to Soro; we agreed she would return by train that evening. She called in early afternoon to be picked up from the train. She was very tired, although she had breaks during the day.

17-09-2013 Natasja can't leave this morning, very unwell, nausea and headaches. Sleeps a lot until I get home in afternoon. Rests in her room.

18-09-2013 When she was going to bed she called that she had lost feeling in her left leg down from her knee. We called the doctor; he said we need to get to Slagelse. He could not find the reason for her problems but said we should not worry. Natasja had severe nausea. The doctor asked for her social security number so that he could look into her situation now and again. We talked about the HPV vaccine and side effects and he said he would call after some months and ask about her.

19-09-2013 Appointment at Glostrup headache clinic. They said they do not know the cause of her headaches, but they would try to find out. They would contact Herlev children's section and ask what they could do. They prescribed amitriptyline 10 mg and to increase with one every week until she reaches 7 each night. Sleepless, dizzy and unwell.

30/09/2013 Natasja tries to go to school every day. They made a room and bed available so she could rest when she is unwell. She avoids the morning assembly because of the noise.

04-10-2013 She stays home, sore throat, feels very ill, maybe it's because she increased to 3 x 10 mg amitriptyline at night. Vision disorders.

11-10-2013 Goes back to school, but couldn't do gym so she just took pictures of the others.

14-10-2013 Autumn holiday, very tired and uncomfortable almost every day. Vision disorders.

17-10-2013 and 18-10-2013 Vomits both nights after she increases to 4 x 10 mg amitriptyline. Vision disorders.

19-10-2013 Went to birthday party. Vision disorders.

20-10-2013 Very sad, severe headache.

21-10-2013 Four hours a day at school in the lower grades. It is relatively ok because it is not so long each day. Tired when she gets home, headaches.

29-10-2013 Frederiksberg Hospital.
Diagnosis: POTS.

31-10-2013 Very dizzy, unwell, can hardly do anything.

04-11-2013 Woke up with resting pulse rate of 159.

05-11-2013 Ill since 31-11-2013. Dizzy, tired. Measure pulse 24 hours a day. Average is 99, the lowest it has been is 80, and the highest was 173.

06-11-2013 Had to be picked up from school at 13.00. She felt that her pulse was throbbing up in her throat.

15-11-2013 to 04-12-2013. Still bad headache, pain in legs, heart throbbing, sleepless. Has had very sore throat for almost 14 days, doctor took tests but negative result for throat infection. Can't go to school because she can't stand noise when she is so fatigued and has intense headache.

05-12-2013 Natasja has still hardly been to school. They called from Glostrup and said we should stop amitriptyline, as it has no effect. Advised to start her on gabapentin 300 mg instead and to increase by 300 mg until she is up to 900 mg a day.

06-12-2013 Have contact with Louise from Frederiksberg as Natasja is doing so badly. She said we'd talk again in 14 days and that maybe Natasja would be given other medicine.

19-12-2013 Takes 900 mg gabapentin now, but headache's still the same. Natasha has lost 10 kg in 3 weeks; her body is very bloated as though there is a lot of fluid retention. Her legs tingle all the time right down to the toes, very uncomfortable. Menstruation came 14 days later than usual with severe pain for 2 days.

20-12-2013 Swelling in extremities - especially legs. Headache. Slight improvement when increased amitriptyline to 50 mg + gabapentin 900 mg. Dizzy. We try midodrine (Gutron) 2.5 mg x 3.

02-01-2014 Headache. No improvement despite amitriptyline and gabapentin. Dizzy - improvement of both dizziness and swollen legs at start up with Gutron 2, 5 mg x 3. Now dizzy again. No effect from use of compression stockings.
We agree to try Gutron 5 mg x 3.

14-01-2014 Improvement regarding swelling in legs. Blood pressure 143/70 in the evening - not a resting blood pressure, pulse 70.

15-01-2014 Natasja is so ill and sleepless because of pain. Called emergency medical service who gave her a morphine tablet so she could get some sleep.

22-01-2014 Intense pain again. Called doctor who said I should drive her to Holbaek. They examined her but could not find anything abnormal. She went to the toilet and collapsed. She said it was as though her legs could not keep her up any more because of pain in the muscles.
Natasja was re-admitted into hospital. She is still there today, 28th January 2014.

Symptoms:

Severe headache.
High pressure in the head.
Visual disturbances.
Dizziness and confusion.
Difficulty concentrating.
Sleeplessness.
Cannot cope with questions.
Difficulty in making decisions.
Sweating and freezing at the same time.
Cold fingers and legs.
Unwell and gets headache in noisy surroundings.
Chest pain and palpitations.
Nausea almost all the time.
Muscular pain.
Stomach pain.
Bloated body.
Swollen legs.
Pain in legs.
Difficulty walking.
Tension and pain in neck and back.
Swollen tonsils.
Frequent vomiting.
Swollen lymph nodes.
Mouth ulcers.
Dry mouth.
Heartburn.
Feel faint.
Fatigue.
Feel pressure in chest.
High pulse.
Heart throbbing.
Hands tremble.
High pulse.
Diarrhoea.
No appetite.
Weight loss.

Diagnosis: POTS