

Patient cases

Niels Ellitsgaard

Odense May 27th 2025



4 year old girl, spinal muscular atrophy type 2, 3 copies, treated with Zolgensma in 2022.

She stands with light support or in her walker. Clinically, left adductor contracture.

24/8 2023; physio: Extended Hammersmith Functional Motor Scale for SMA (HFMSE). Score = 31 / 66 – which is 2 points higher than previously. She is becoming increasingly stable around the hips and can now stand briefly with hand support on the bench.

X-ray of the hips shows increasing lateralization/migration of both hips. Both femoral heads show lateral eccentric ossification centers, the left almost completely uncovered, the right 50% uncovered. Pubo-femoral distance bilaterally > 10 mm.

Operated on 18/1 2024 with 30-degree proximal varus femur osteotomy using OrthoPediatrics PediLoc child angled plate and Dega periacetabular pelvic osteotomy. A 1 cm femoral diaphyseal graft to the pelvis. Psoas lengthened over the brim.

Subsequently braced with femur cuffs and abduction bar for 5 weeks. After unbracing, increased rehabilitation based on a rehabilitation plan (GOP).

Post-op physio test 19/9 2024: Can crawl again, slowly for 2–3 meters, can also scoot using her arms, also sits on knees and plays. Significant problems with physiotherapy services and the loaned mobility aid has been taken from the home.

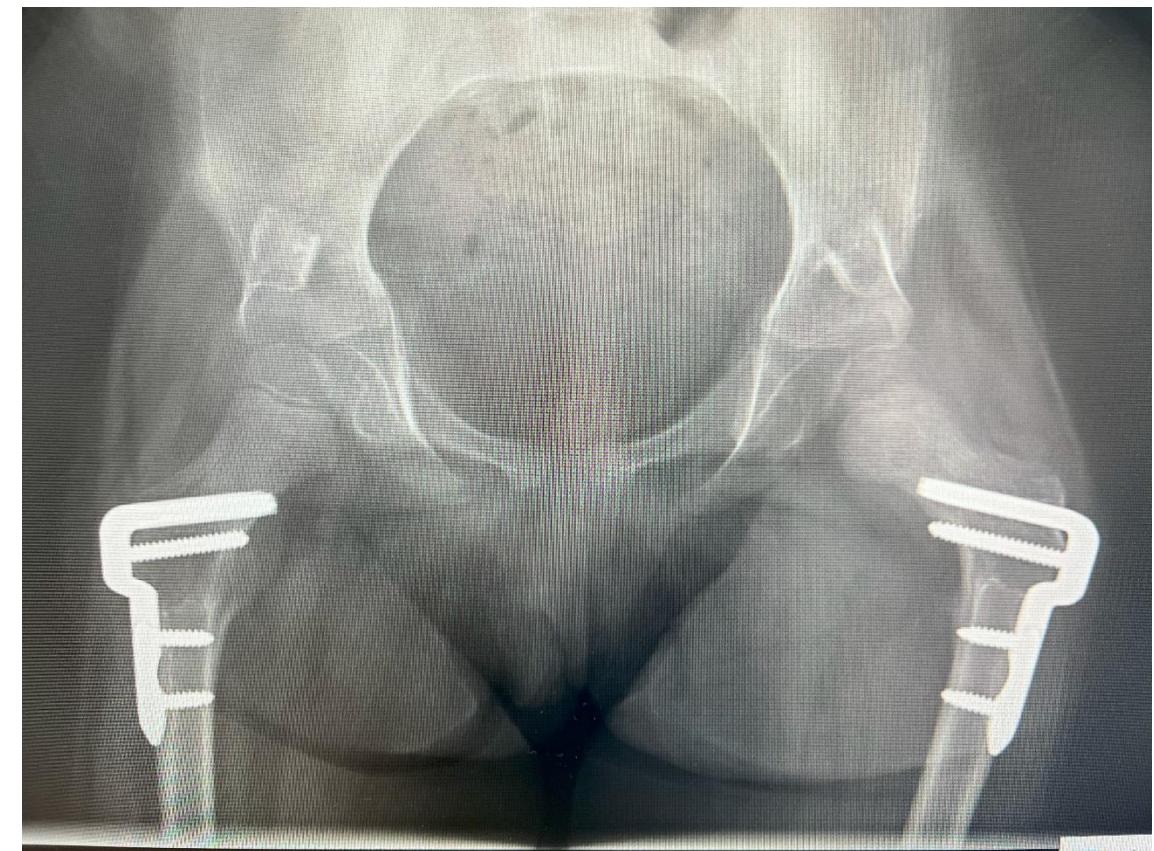
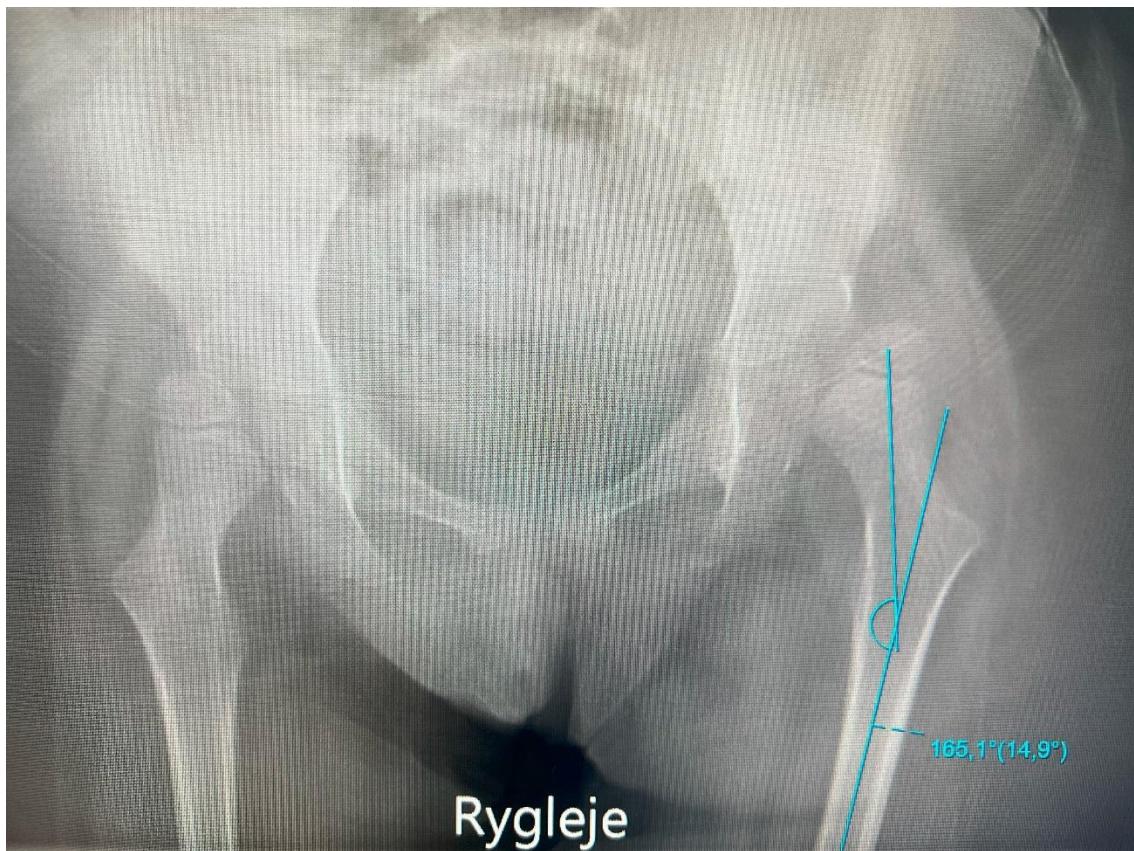
A new GOP has been returned; the municipality believes she has been sufficiently rehabilitated!

Niels Ellitsgaard

Aug. 2023

Surgery jan. 24

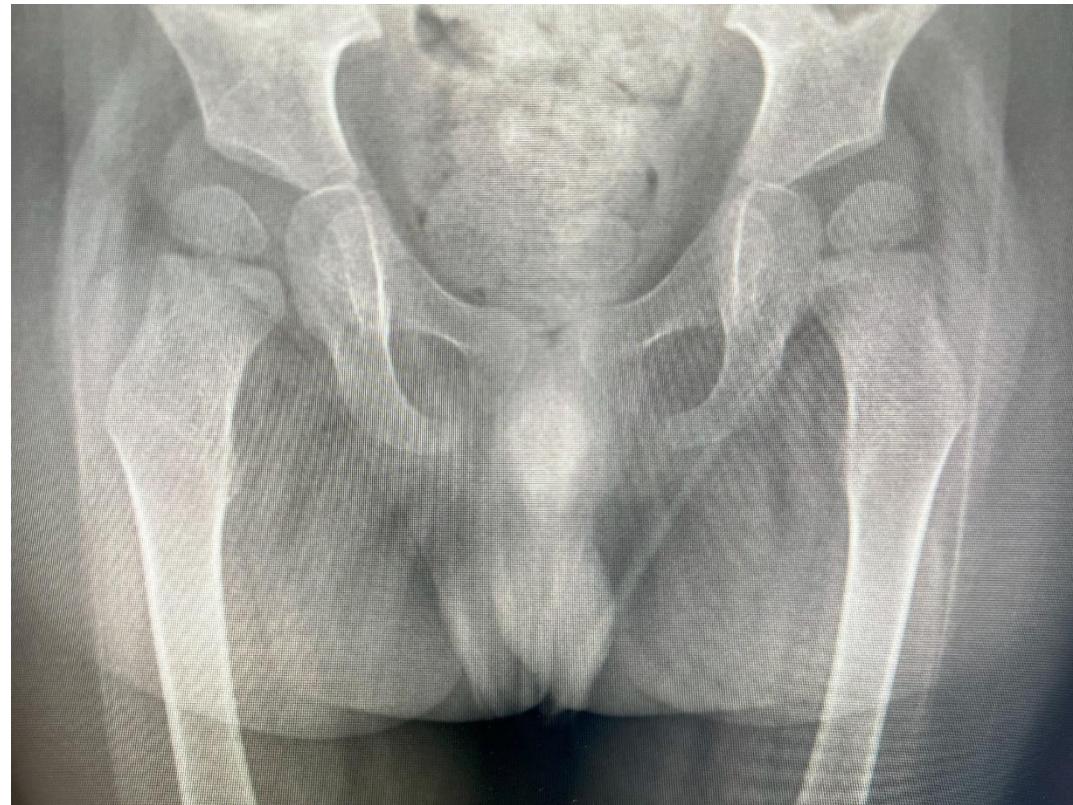
Sept. 2024



TT, 4.5 years male, was born with spinal muscular atrophy type 2 with 3 SMN2 copies, currently undergoing Spinraza treatment. Last intrathecal dose of Nusinersen on 16/1 2024.

- Crawls around and stands in a standing frame. Increasing adductor tightness and now complains of hip tenderness after activity. CPAP and cough assist. Respiratorily stable. Hammersmith 2/8 24: 31/66
- X-ray of hips bilaterally shows bilateral sub-luxation, clearly worsened over the last two years, although with only modest proximal migration. Bilateral acetabular dysplasia.
- Planned surgery on 21/11 2024: adductor tenotomy, psoas over the brim and guidet growth bilaterally

Dec 2021

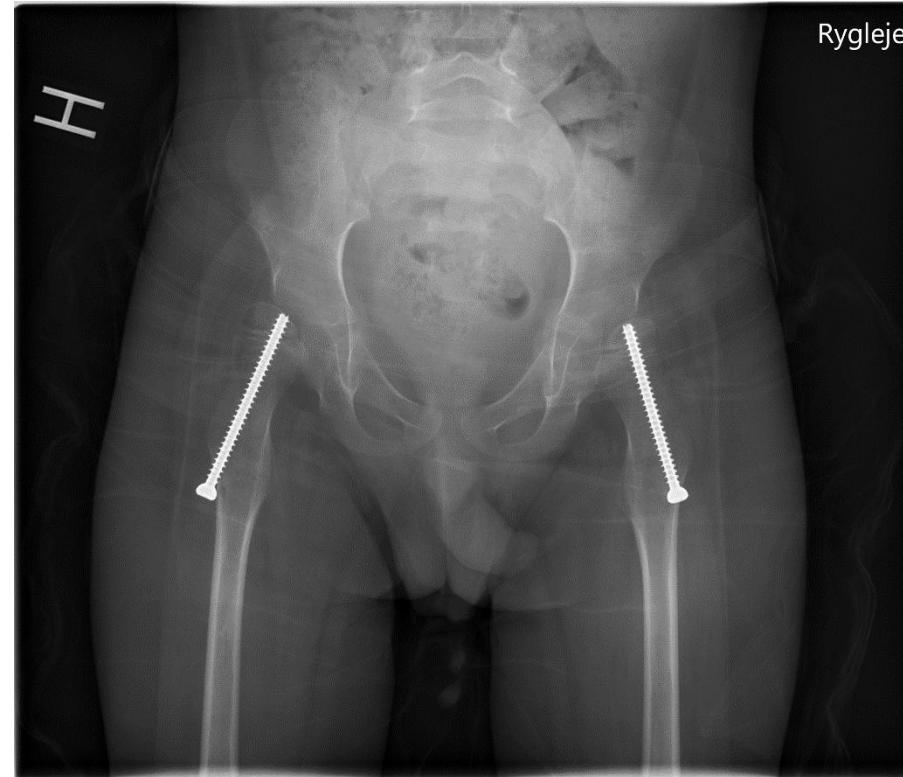


TT, male 7 years



July 2024

TT, male 8 years, 6 weeks postopr



- **2020, currently on Risdiplam.**

- **Motor function**

Good progress. Home training with "Neuro Potential" by Henrik Kirk.

Uses KAFO and walker (Martin walker with forearm support), which she likes. Previously used a soft support corset. Can transfer herself and goes to the toilet independently. Has both a manual and electric wheelchair, and an electric bicycle.

- Has difficulty standing due to contractures. She has been promised that we might help her with 8-plates.

- HFMSE April 24th 2025 32/66.

- Today, she presents with a strong will to demonstrate her abilities in transfers and dressing/ undressing. Lifts herself with upper extremities, free joint mobility.

- Brings KAFO made by Toni Jansen with both outer and inner heel wedges, accommodating both knee contracture and slight calf tightness.

- **Examination on the bench:**

Psoas tightness. Can abduct hips to 2 x 30 degrees.

Popliteal angle: 70 degrees. Knee contracture: 20–30 degrees.

With "extended" knees, ankle dorsiflexion is limited 20 degrees before neutral.

All joint limitations present a springy stop and expressions of discomfort.

- Presents with a scoliosis X-ray showing a straight spine, consistent with clinical findings.

- X-rays from the past 3 years show increasing bilateral migration.

The most recent X-ray from May 2024 shows 50% bilateral migration. The AI (Acetabular Index) cannot be assessed due to a tilted pelvis.

- Had a long conversation with father about the need for 8-plates and now also about both hips, which have migrated so far that I believe hip reconstruction is indicated.



FN girl age 6, SMA-2 3 cop

Febr 2023 and May 2024

