

Missie Tumor Onbekend: CUP patient advocacy organisation & charity in the Netherlands



June 2018

Hederik begins experiencing double vision in one eye, which is monitored by an orthoptist over the summer

September 2018 - December 2018

Blood tests, spinal fluid test, diverse imaging (CT, MRI, PET, as well as gastric scans) follow, with doctors across 3 hospitals considering tropical diseases, cancer, and autoimmune disorders

January 2019

After a diagnosis of unfavourable CUP, Hederik begins empirical chemotherapy. He passes away suddenly the next day

August 2018

Hederik has a first CT scan of his brain, revealing a lesion on his cranial nerve – many possible diagnoses emerge

December 2018

Hederik is diagnosed with CUP on Christmas Eve after a risky cranial nerve biopsy, revealing leptomeningeal metastases

2020

I co-founded Missie Tumor Onbekend and became a CUP patient advocate

Our goals

- 1. Raise awareness, and get the 'unknown' out of CUP
- 2. Increase quality of care & life for patients and their families
- 3. Increase the chance of survival & decrease CUP incidence

Our ultimate ambition: No more newly-diagnosed patients and/or perspective towards a cure

CT: computed tomography; CUP: cancer of unknown primary; MRI: magnetic resonance imaging; PET: positron emission tomography.

