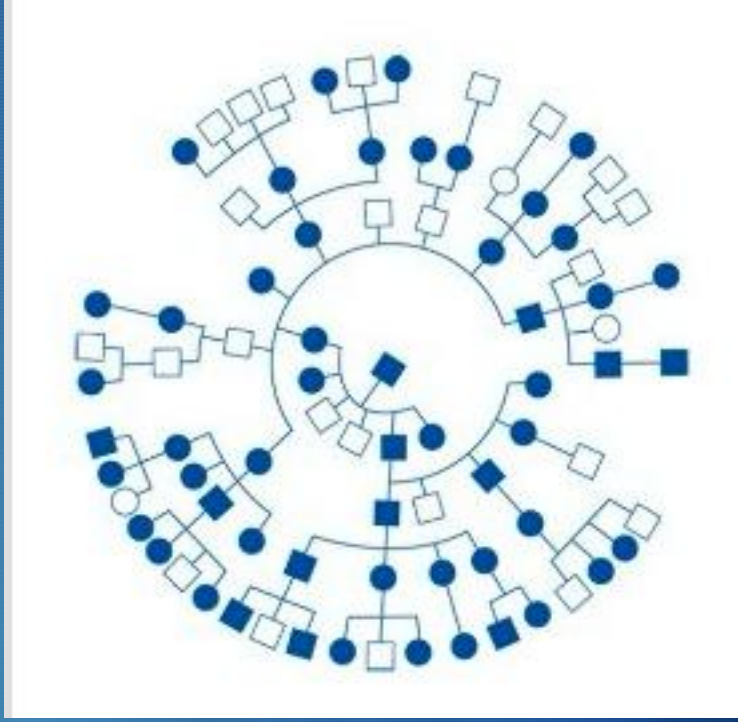
StOET



The Netherlands Foundation for detection of Hereditary Tumors

Background

- 1985 national initiative to register all families with a hereditary form of cancer; initiative of different academic centers and the Netherlands Cancer Institute
- Mission; Prevention of cancer related mortality by early detection of hereditary tumors
- Improvement of medical care; recall system and monitoring of quality of care

Background; LS

- Several studies haven proven that colonoscopy surveillance for Lynch syndrome reduces CRC incidence and associated mortality with > 50%[1,2]
- However, interval cancers do exist! [3,4]
- Quality of colonoscopy is of utmost importance, however not optimal [5,6]
- Surveillance interval is not followed correctly

[1]De Jong AE, Gastro 2006, [2]Jarvinen HJ, Gastro 2006, [3]Dominguez-Valentin M Genet Med 2020, [4]Sanchez A CGH 2020, [5]Leerdam van ME, Endoscopy 2019, [6]Argillander TE, UEG J 2018

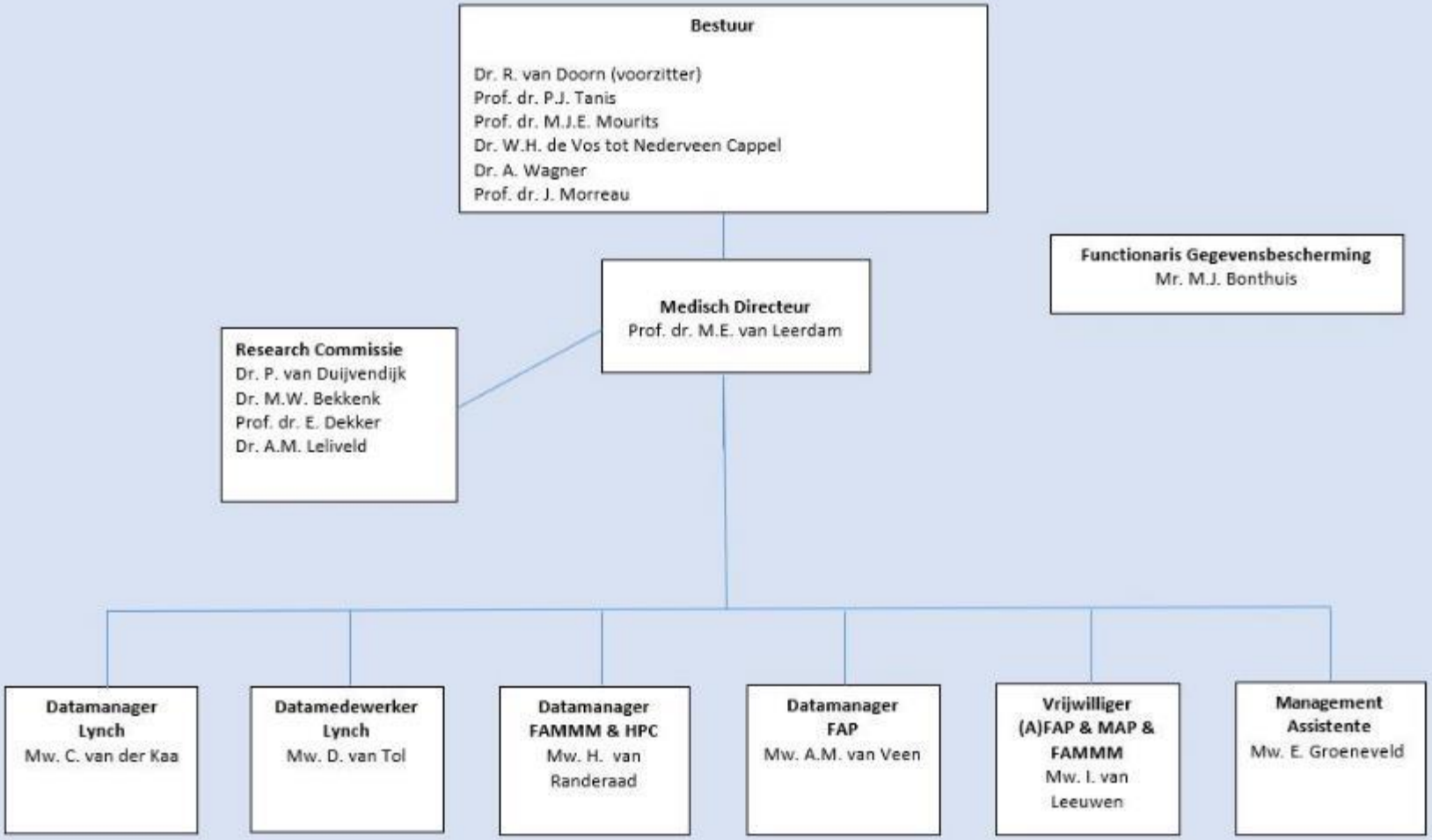
Background; LS

- International studies have shown that a national registry with recall system lead to high adherence of surveillance programs [1]

- ESGE guideline[2];' For these reasons, individuals with LS should be followed in dedicated units (national registries, genetic counseling centers, or high-risk cancer centers) where endoscopic surveillance recommendations **are monitored** in order to improve **adherence** and **to audit the quality** of the surveillance program.

[1]Sjostrom O, Fam Cancer 2016, [2]Leerdam van ME Endoscopy 2019

Dutch foundation for the detection of Hereditary Tumors



Different tasks

- Registry based on informed consent of high risk individuals
- Recall system
- Data processing of results of endoscopy/ gynecology/skin surveillance, resection reports etc.
- Information for patients, family-members, medical specialists
- Guidelines for diagnoses and prevention of hereditary cancers (in collaboration with clinical genetics)

Different tasks

- Communication of quality indicators to gastroenterologists (monitoring system); Number of endoscopies for LS, CIR, ADR, interval CRC (benchmarking)
- Evaluation of the Dutch care. Research based on anonymized data using the national database

Scientific publications

- 2021; Lack of association between CDKN2A germline mutations and survival in patients with melanoma: A retrospective cohort study
- 2018; No difference in CRC or stage at detection by colonoscopy among 3 countries with different Lynch syndrome surveillance policies
- 2012; Risk of less common cancers in proven mutation carriers with lynch syndrome.
- 2018; Extracolonic cancer risk in Dutch patients with APC-associated polyposis.

Improvement

- AVG proof; European law
- Coverage in NL around 70%, aiming for 100%
- > 12,500 persons based on IC registered
- National database system for LS, FAP, MutYH, PTEN, PJS, POLE/POLD1, FAMMM/CDKN2A, familial prostate carcinoma (familial/ hereditary breast cancer)
- Adding other syndromes (stomach cancer, p53 etc)

StOET

- Request for data at the different Dutch hospitals (N=92)
- Collaboration of gastroenterologists throughout the Netherlands; authorship in publications

Collaboration/ finances

- Collaboration with all Dutch hospitals
- Until 2014 payed by a continuous grant of the government.
  Currently paid by the different hospitals based on LS/polyposis diagnosis (to be settled with the health insurer)

The Netherlands Foundation for detection of Hereditary Tumors www.stoet.nl

ERFELIJKE TUMOREN (StOET)

HOME REGISTRATIE ZIEKTEBEELDEN ARTSEN INFORMATIE WETENSCHAPPELIJK ONDERZOEK ORGANISATIE CONTACT