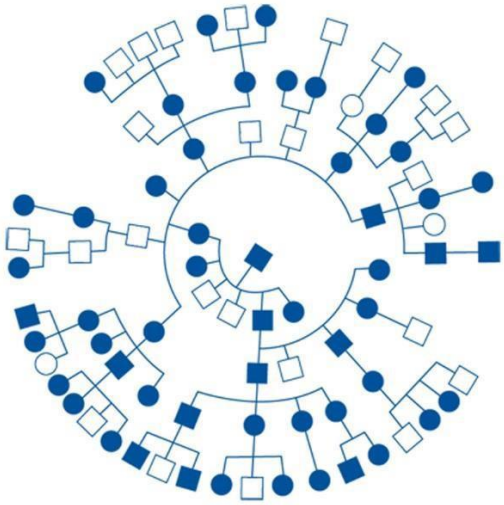
Annual Report

2023

The Netherlands Foundation for the Detection of Hereditary Tumors

Stichting Opsporing Erfelijke Tumoren (StOET)



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MISSION

The mission of the Foundation for the Detection of Hereditary Tumors (hereinafter referred to as StOET) is to prevent unnecessary death by early detection of hereditary tumors. To achieve this, the national registry offers its support in the management of patients genetically predisposed to the development of cancer. The registry helps to identify all persons within an affected family and to provide information regarding their greatly increased risk of cancer and the importance of preventive surveillance examinations. It also monitors the quality of care and adherence to the necessary lifelong surveillance. In addition, the Foundation is a port of call for patients and families. The registry promotes scientific research with the joint aims of improving screening programs and increasing our understanding of hereditary tumors. All activities described in this annual report were designed to help accomplish the above mission.

1. GENERAL ISSUES

Monique van Leerdam as the Medical Director

In January 2019, Professor Monique van Leerdam MD, PhD, gastroenterologist and clinical epidemiologist, has become medical director of the StOET. She has a long record of excellent research in Lynch syndrome and polyposis syndromes. Prof. Dr. van Leerdam is a senior staff member of the Department of GI-Oncology at the National Cancer Institute (Antoni van Leeuwenhoek) in Amsterdam. In addition to her appointment as Medical Director of the registry, she is senior staff member and head of the Family Cancer Clinic at the Leiden University Medical Center in Leiden.

Protection of privacy in accordance with new European legislation: AVG

The Registry keeps a record of medical data relating to patients and risk-bearing family members. The processing of such data has been subject to the General Data Protection Regulation (AVG) since May 25, 2018. The AVG sets out the conditions under which personal and medical data can be processed and also defines the rights of subjects involved. In agreement with the AVG, the StOET will only initiate registration once the person concerned has given written permission. In 2018 the Supervisory Committee for the Protection of Privacy was abolished and instead a privacy officer was appointed at the StOET, with a mandate to ensure that the rules on privacy are adhered to. Since December 2020 the StOET has a new privacy officer, Marie-José Bonthuis, with experience in other large database consortia. If a person registered with the StOET wishes to exercise his or her rights in accordance with the AVG, this can be done by sending a message to the following email address: privacy@stoet.nl.

Secure communication solutions

E-mail is an indispensable part of communication for the StOET and the specialists (and in some cases with patients). In 2019 ZorgMail Secure e-mail has been implemented which means that the StOET can receive and send e-mails with privacy-sensitive information in a the most secure environment possible.

European Hereditary Tumour Group (EHTG) Guideline

In 2023 Anja Wagner, board member of the StOET, attended the EHTG annual meeting in Vilnius.

InSIGHT (InSiGHT (insight-group.org)

In 2023 there was no InSIGHT meeting

2. REGISTRATION

2.1 Registration of new family members

The number of subjects referred for registration is increasing yearly. Table 1 shows the current numbers of registered individuals, listed according to hereditary cancer syndrome.

Table 1. Number of individuals registered at the StOET on January 1st, 2023

Syndrome	Number of individuals registered 01-01-2023	Number of individuals registered 01-01-2023 but deceased
Lynch syndrome/ Familial Colorectal cancer	4581	578
Familial Adenomatous Polyposis/ poliposis	3093	488
Familial Atypical Multiple Mole Melanoma	5654	983
Familial prostate cancer	1828	540
Peutz-Jeghers syndrome	50	12

2.2. Reminder system

The StOET has a reminder system with the aim of guaranteeing the progress of lifelong screening. In practice this entails the sending of a message from the StOET to the treating specialist in which it is made clear that a certain patient is (again) eligible for screening examinations.
The specialist then sends the result of the examination to the registry (or a copy of the letter to the general practitioner) and informs the StOET regarding scheduling of the next screening round.
In 2022 all specialists caring for persons registered at the StOET were informed in this way. If it emerged that a particular individual had withdrawn from screening, action was taken. First the patient received a reminder to attend the examination from the specialist. In case of no response, the general practitioner was then asked to remind the patient of the importance of periodic examinations. This approach helps prevent the loss of patients from screening who might later present with complaints that in many cases are due to a carcinoma.
For FAP the reminder system has been digitalized meaning that reminders are sent by secured mail system and information is received by secured mail.

2.3 Information about the different hereditary syndromes.

All information about the different hereditary syndromes has been updated on the website (www.stoet.nl) over the last years and in 2023. This information is meant both for treating physicians as well as for patients.

3. EVALUATION OF SURVEILLANCE

As stated in our mission, the registry promotes scientific research with the aim of improving surveillance programs. Currently several programs are being evaluated. Below a number of studies is listed related to surveillance conducted or published in 2023.

4. NATIONAL GUIDELINES

In 2022 StOET and the working group clinical oncogenetics (WKO) from the Society for Clinical Genetics Netherlands (VKGN) have published the first digital version of the ‘Erfelijke en familiaire

tumoren; richtlijnen voor diagnostiek en preventie'. This modular version with a summary of all Dutch guidelines and recommendations for hereditary syndromes will be updated as soon as new publications are available, hereby delivering the most up to date information to care providers (Richtlijnen boekje Stichting opsporing erfelijke tumoren (stoet.nl)).

5. EDUCATION, PUBLICATIONS AND PATIENT INFORMATION

After a period of complete lock down due to the COVID10 pandemic, which caused many cancellations of presentations and patient information days were cancelled, the presentation for the Lynch Polyposis Patient association was held in November 2023 in Zeist, and joined by approx. 100 persons. The StOET has given a presentation about the work of the StOET. The medical director has given a presentation about immunotherapy treatment in hereditary coloncancer syndromes. Mutual collaboration between the patient association and StOET is important in order to emphasize the importance of being registered at the StOET and exchange of information.

In November 2023 the StOET organized the patient information day about Hereditary Melanoma and Hereditary Pancreatic Cancer syndrome together with the department of Dermatology and the department of Gastroenterology and Hepatology of the Leiden Universitair Medisch Centrum, Leiden.

The StOET joined the kick-off of a new national initiative: the Nederlands Kanker Collectief (Dutch Cancer Collective).

Several articles about hereditary cancer syndromes have been published in the Lynch Polyposis information magazine for patients, https://www.lynch-polyposis.nl/polyposis/publicaties-stichting-lynch-polyposis/

In addition, many articles were published with the aim of increasing knowledge regarding hereditary cancer for professionals (see below).

The leaflets produced by the StOET on various hereditary forms of cancer were updated where necessary. The StOET website is updated regularly by Evelyn Groeneveld.

In March 2023 a specific college for second years students about hereditary GI cancers was given by prof. van Leerdam at the Leiden University Medical Center.

6 . OTHER STUDIES/ PUBLICATIONS

Guidelines

European Hereditary Tumour Group (EHTG) guideline.

Wagner A, Aretz S, Auranen A, Bruno MJ, Cavestro GM, Crosbie EJ, Goverde A, Jelsig AM, Latchford A, Leerdam MEV, Lepisto A, Puzzono M, Winship I, Zuber V, Möslein G.The Management of Peutz-Jeghers Syndrome: The Management of Peutz-Jeghers Syndrome: European Hereditary Tumour Group (EHTG) Guideline.
J Clin Med. 2021 Jan 27;10(3):473

European Society of Gastrointestinal Endoscopy (ESGE) guideline.

van Leerdam ME, Roos VH, van Hooft JE, Dekker E, Jover R, Kaminski MF, Latchford A, Neumann H, Pellisé M, Saurin JC, Tanis PJ, Wagner A, Balaguer F, Ricciardiello L. Endoscopic management of polyposis syndromes: European Society of Gastrointestinal Endoscopy (ESGE) Guideline. Endoscopy. 2019;51:877-895.

van Leerdam ME, Roos VH, van Hooft JE, Balaguer F, Dekker E, Kaminski MF, Latchford A, Neumann H, Ricciardiello L, Rupińska M, Saurin JC, Tanis PJ, Wagner A, Jover R, Pellisé M. Endoscopic management of Lynch syndrome and of familial risk of colorectal cancer: European Society of Gastrointestinal Endoscopy (ESGE) Guideline. Endoscopy. 2019;51:1082-1093.

Hereditary pancreatic cancer.

Surveillance for Pancreatic Cancer in High-Risk Individuals Leads to Improved Outcomes: A Propensity Score-Matched Analysis. Klatte DCF, Boekestijn B, Onnekink AM, Dekker FW, van der Geest LG, Wasser MNJM, Feshtali S, Mieog JSD, Luelmo SAC, Morreau H, Potjer TP, Inderson A, Boonstra JJ, Vasen HFA, van Hooft JE, Bonsing BA, van Leerdam ME; Dutch Pancreatic Cancer Group. Gastroenterology. 2023;164(7):1223-1231.

Psychosocial issues of individuals undergoing surveillance for increased risk of melanoma and pancreatic cancer due to a germline CDKN2A variant: A focus group study.Klatte DCF, Onnekink AM, Hinnen C, van Doorn R, Potjer TP, van Leerdam ME, Bleiker EMA. J Genet Couns. 2023. Online ahead of print.

Poliposis syndrome

Colibactin mutational signatures in NTHL1 tumor syndrome and MUTYH associated polyposis patients. Terlouw D, Boot A, Ducarmon QR, Nooij S, Jessurun MA, van Leerdam ME, Tops CM, Langers AMJ, Morreau H, van Wezel T, Nielsen M. Genes Chromosomes Cancer. 2023.. Online ahead of print.

APC mosaicism, not always isolated: two first-degree relatives with apparently distinct APC mosaicism. Terlouw D, Hes FJ, Suerink M, Boot A, Langers AMJ, Tops CM, van Leerdam ME, van Asperen CJ, Rozen SG, Bijlsma EK, van Wezel T, Morreau H, Nielsen M. Gut. 2023 Nov;72(11):2186-2187.

Personalized endoscopic surveillance and intervention protocols for patients with familial adenomatous polyposis: the European FAP Consortium strategy. Aelvoet AS, Pellisé M, Bastiaansen BAJ, van Leerdam ME, Jover R, Balaguer F, Kaminski MF, Karstensen JG, Saurin JC, Hompes R, Bossuyt PMM, Ricciardiello L, Latchford A, Dekker E; European FAP Consortium. Endosc Int Open. 2023;11(4):E386-E393.

Cold snare polypectomy for duodenal adenomas in familial adenomatous polyposis: a prospective international cohort study. Aelvoet AS, Karstensen JG, Bastiaansen BAJ, van Leerdam ME, Balaguer F, Kaminski M, Hompes R, Bossuyt PMM, Ricciardiello L, Latchford A, Jover R, Daca-Alvarez M, Pellisé M, Dekker E; European FAP Consortium. Endosc Int Open. 2023 Nov 10:E1056-E1062.

van Liere ELSA, de Boer NKH, Parsan EA, van Leerdam ME, Ramsoekh D; Netherlands Foundation for Detection of Hereditary Tumours collaborative investigators. Effect of the COVID-19 pandemic on endoscopic surveillance in Lynch syndrome in the Netherlands. Lancet Gastroenterol Hepatol. 2023;8(6):504-506.

Helderman NC, Van Der Werf-'t Lam AS; MSH6 TUMOR GROUP; Morreau H, Boot A, Van Wezel T, Nielsen M. Molecular Profile of MSH6-Associated Colorectal Carcinomas Shows Distinct Features From Other Lynch Syndrome-Associated Colorectal Carcinomas. Gastroenterology. 2023;165(1):271-274.

Eikenboom EL, Moen S, van Leerdam ME, Papageorgiou G, Doukas M, Tanis PJ, Dekker E, Wagner A, Spaander MCW; collaborative investigators from the Dutch Foundation for Detection of Hereditary Tumors. Metachronous colorectal cancer risk according to Lynch syndrome pathogenic variant after extensive versus partial colectomy in the Netherlands: a retrospective cohort study. Lancet Gastroenterol Hepatol. 2023:12:1106-1117. .

7 . ORGANIZATION

7.1. Board

Dr. R. van Doorn (chairman), dermatologist, Leiden University Medical Center, Leiden
Dr. W.H. de Vos tot Nederveen Cappel, gastroenterologist, Isala Clinics, Zwolle
Prof. Dr. M.J.E. Mourits, gynaecologist, University Medical Centre Groningen, Groningen (until 1/9/2023)
Dr. H. C. van Doorn, gynaecologist, Erasmus Medical Centre, Rotterdam (per 1/9/2023)
Dr. A. Wagner, clinical geneticist, Erasmus Medical Centre, Rotterdam
Prof. Dr. P. Tanis, professor of colorectal surgery, Erasmus Medical Center, Rotterdam
Prof. Dr. J. Morreau, pathologist, Leiden University Medical Center, Leiden

7.2. Registry staff

Prof. Dr. M.E. van Leerdam, gastroenterologist, Medical Director
E.M. Groeneveld, management assistant
A.-M. van Veen, registration Familial Adenomatous Polyposis/ poliposis
I.S.J. van Leeuwen-Cornelisse, medical social worker (until 30/9/2023)
H.L. van Randeraad, registration Hereditary Melanoma and Hereditary Prostate cancer
L. van Leeuwen, registration Lynch syndrome
D. van Tol, registration Lynch syndrome

7.3. Data Privacy Officer

Mr. M.J. Bonthuis

7.4. Research Commission

Dr. P. van Duijvendijk, surgeon, Gelre Hospital, Apeldoorn
Prof. dr. E. Dekker, gastroenterologist, Amsterdam University Medical Centre, Amsterdam
Dr. A.M. Leliveld, oncological urologist, University Medical Centre Groningen, Groningen
Prof. Dr. M. Bekkenk, dermatologist, Amsterdam University Medical Centre, Amsterdam
S. ten Broeke, clinical geneticist in training, University Medical Centre Groningen, Groningen

ENCLOSURES

Presentations

1. Hereditary GI cancer syndromes; University college March 2023
2. De StOET omdat het 'moet'. Presentation on the Lynch Poliposis patient information day, November 2023, Zeist
3. Immunotherapie in erfelijke darmkanker syndromen. Presentation on thee Lynch Poliposis patient information day November 2023, Zeist
4. Organisation of the patient information day Hereditary Melanoma and Hereditary Pancreatic Carcinoma with several presenations, Leiden Universitair Medisch Centrum, Leiden.
5. Attendance of the Melanoma Patient information Day on April 1th 2023