

NF 1 landelijk netwerk

Activiteiten 2023

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3 april 2023



Netwerk- rapportage 2022/2023

Rapportage 2022 (d.d. januari 2023)

besproken in **bijeenkomst Kwaliteitscommissie** (7 februari 2023)

Terugkoppeling aan de centra: 2^e kwartaal 2023

Aankondiging

Eind december 2023 input gevraagd ten behoeve van Rapportage 2023 !

Overig

- Zorgpad MEKi via CUP Astra Zeneca

4 kinderen, 1 adolescent onder behandeling (3 – 18m)

3m bezoeken in EMC, met labcontrole in eigen regio

1 gestopt ivm bijwerkingen, 1 afbouw traject vanwege onv effect
evaluatie zorgpad zomer 2023

- Op naar gestandaardiseerde dossiervoering en landelijke registratie

HIX 6.2 GLM voor NF1 ook elders toegankelijk?

Minimal dataset voor LNHS - op naar registry?

Research (update)

QOL in NF1

Validatie SKINdex-NL: 28 inclusies (60), analyse juni 2023

Validatie Plexiqol: 35 inclusies (40), analyse mei 2023

SPRINKLE trial

granula formulae of Koselugo in children 1-<7 yr with inoperable PN

24m duration (1 eligible afgewezen)

www.nf1-expertise.net/research/

Research (update)

EU-PEARL Development platform trials in NF (www.eu-pearl.eu)

loopt tot eind april 2023

concept platform trial NF1 cutNF, PNF, LGG en OPG

-Implementatie LNHS data in routine zorg

-Verstevigen internationale samenwerking (EU en USA)



EU-PEARL
EU PATIENT-CENTRIC
CLINICAL TRIAL PLATFORMS

www.nf1-expertise.net/research/

Research (nieuw)

DAISY studie

TRAIN?

www.nf1-expertise.net/research/

Oproep Daisy-onderzoek NF 1 en kwaliteit van leven

XXX



NF1 – awareness day 17 mei 2023



RUNExpected op 14 mei !

Meedoen? <https://www.runexpected.nl/participate/how-to-participate>

Doneren? Steun ons!!: <https://www.runexpected.nl/teams/expertisecentrum-erasmus-mc>

NF congressen 2023

CTF meeting 24-27 juni 2023

Arizona

<https://www.ctf.org/get-involved/nf-conference>

SAVE THE DATE

2023 NF CONFERENCE
JUNE 24 - 27, 2023
FAIRMONT SCOTTSDALE HOTEL
SCOTTSDALE, ARIZONA

NF CONFERENCE

2023 NF Conference

June 24-27
Fairmont Scottsdale
Princess, Arizona

The 2023 NF Conference will be a hybrid event, offering both in-person and virtual attendance options.

Registration is now open.

Abstract Submission Deadline has been extended to March 31, 2023.

Questions? Contact Angela Dumadag at adumadag@ctcf.org or 646-738-8553.

In 2024, the Global NF Conference will be held in Brussels, Belgium | June 20-25, 2024

REGISTER
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AGENDA
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ABSTRACT SUBMISSION
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PROGRAM & ABSTRACT BOOK
Coming in June 2023

Sign up to get the latest news and announcements from the Children's Tumor Foundation

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EANO 2023: 21-24 september 2023

Rotterdam

Indienen van abstracts voor presentaties (posters of mondeling) is mogelijk tot en met 6 april. Zie

<https://www.eano.eu/eano2023/abstracts/>

NF1 – nascholing



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CTF EUROPE TRAVEL GRANTS

Children's Tumor Foundation Europe is offering travel grants to a selection of multidisciplinary NF centres throughout Europe. Participating clinics offer a pre-programmed 1-to 3-day visit, as well as à la carte training.

<https://www.ctfeurope.org/research/ctf-europe-travel-grants>

NF1 – nascholing

Mar 17: Cognition and Behaviour in NF1:
Phenotype and Treatment Approaches

Apr 15: Surgery in NF2

Recordings of Past Events

MASTERCLASSES IN NF

A series of online educational lectures
for medical professionals by leading
neurofibromatosis experts

Reserve your spot today:

ctfeurope.org/nfmasterclasses

Supported by an educational grant from AstraZeneca



INFER

INTERNATIONAL
NF
EDUCATIONAL
RESOURCES



Erasmus MC



Sophia Kinderziekenhuis

NF1- nascholing ERN Genturis



ERN GENTURIS Webinars <https://www.genturis.eu/l=eng/Education-and-Training/Webinars.html>

Target audience for the webinars are clinicians, genetic counsellors, clinical scientists and other genetics health professionals. Webinars are usually held on Wednesday afternoons.

Date	Time	Speaker	Title
26-04-2023	16:00-17:00 CEST	Marc Tischkowitz and Judith Balmaña	Mainstreaming – method or madness?
10-05-2023	16:00-17:00 CEST	Rolf Sijmons	Liquid biopsy: the future of surveillance in individuals with inherited cancer predisposition?
07-06-2023	16:00-17:00 CEST	Gareth Evans	New ERN GENTURIS NF1 guidelines and update on NF2 and SCHWN nomenclature

Netwerk-agenda 2023/2024

- Jubileumcongres NFVN Breukelen 15 april 2023
- Feedback gesprekken met BCs vanuit kwaliteitscommissie juni – okt 2023
- Volgende **netwerkbijeenkomst** (casuïstiek): 9 juni 2023
aanmelden bij Sarah van Dijk (s.a.vandijk.1@erasmusmc.nl)
- Volgende bijeenkomst **kwaliteitscommissie**: 6 februari 2024 (data insturen eind dec 2023)
- Volgende **jaarlijkse netwerkdag**: maart 2024 (locatie? organisatie?)
Vertegenwoordiging vanuit BCs en IVCs onderdeel van deelname aan netwerk

THANK YOU

