Vooraanmelding kandidaat expertisecentrum voor zeldzame aandoeningen

Lees graag eerst de toelichting in bijlage 1!

Naam kandidaat expertisecentrum in NL		
Name of aspirant centre of expertise in EN		
Naam 1e contactpersoon		
Mailadres 1e contactpersoon		
Telefoonnummer		
Dit betreft een: (graag aankruisen)		Nieuw EC
		Eerder afgewezen EC
		Reeds erkend met toetsingsnummer:
Betrokken patiëntorganisaties		

Dit centrum wenst zich aan te melden voor de landelijke toetsing in de ronde 2017 en wel voor erkenning van expertise voor de volgende (clusters van) zeldzame aandoeningen:

Naam aandoening		Orphacode
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

BIJLAGE 1: Instructie voor het invullen van het vooraanmeldingsformulier

Stappen:

1. Ga na voor welke expertise, zeldzame aandoeningen, u zich wenst aan te melden.
2. Bekijk op een intern overzicht of op de NFU website het overzicht van eerder erkende centra in uw huis en kijk of er geen sprake is van overlap van expertise.
3. Zo niet, ga dan ook na of er collega's in huis zijn die wellicht voor dezelfde aandoeningen wensen aan te vragen (zeldzame aandoeningen vragen immers veelal om een multidisciplinaire aanpak) en stem af.
4. Bekijk de criteria (bijlage 2), de digitale vragenlijst (bijlage3) en de bijlagen (bijlagen 4) die hierbij dienen te worden ingeleverd en bepaal of uw voor de te erkennen expertise aan de criteria voldoet en hier ook voldoende onderbouwing voor kunt aanleveren.
5. Bepaal vervolgens o.b.v. de separaat meegestuurde Excel sheets van de Orphanet database precies de juiste (clusters van) aandoeningen en bijbehorende Orphacode(s). Dit kunnen er max. 10 zijn en voor eerder erkende expertisecentra een aanvulling tot max. 10.
6. Realiseert u zich dat u voor elk van de specifieke aandoeningen die u opvoert onderbouwing dient te worden aangeleverd (zie digitale vragenlijst).
7. Indien er ook maar enige onduidelijkheid is over de zeldzaamheid van een aandoening, de Oprhanet code van een zeldzame kanker of keuze tussen Orphacodes, neemt u dan s.v.p. zo spoedig mogelijk contact op met Judith Carlier van Orphanet NL. Zij is met uitzondering van 14 t/m 18 juli in de maanden juli en augustus bereikbaar op dinsdag, donderdag, vrijdag via: J.E.Carlier@lumc.nl (voorkeur) of 071-5269411.

BIJLAGE 2: Criteria expertise centrum zeldzame aandoening (o.b.v. EUCERD en NPZZ)

Kwaliteit van zorg
Het EC is - indien relevant voor de specifieke zeldzame aandoening - in staat tot het leveren van hoog gespecialiseerde complexe patiëntenzorg op het gebied van diagnostiek, behandeling en nazorg en follow-up.
Het EC levert inbreng bij ontwikkeling van zorgstandaarden en richtlijnen en werkt mee aan de verspreiding hiervan, samen met vertegenwoordigers van betrokken patiëntenorganisaties.
Het EC levert de zorg met een vaststaand multidisciplinair (MD) team.
Het EC coördineert het zorgaanbod binnen de gehele keten voor de specifieke aandoening.
Binnen het EC is men op de hoogte van en draagt bij aan de meest recente (basaal) wetenschappelijke ontwikkelingen ten aanzien van de diagnostiek, causale en/of symptomatische behandeling en van secundaire en tertiaire preventieve maatregelen en/of van specifieke psychosociale begeleiding van de patiëntengroep.
Het EC beschikt over een systematiek om de kwaliteit van de zorg te waarborgen.
Transitie
Het EC zorgt, waar nodig, voor waarborging van de continuïteit van de zorgverstrekking van kinderjaren, via adolescentie tot en gedurende volwassen leeftijd (transitiezorg).
Continuiteit van EC
Het EC draagt zorg voor de opleiding van c.q. de overdracht van kennis naar (nieuwe) experts van het MD-team.
Het EC is erkend door de Raad van Bestuur.
Het EC is bereid tot visitatie.
Samenwerking met andere partijen
Het EC werkt met patiënten(organisatie(s) samen om de kwaliteit van zorg te verbeteren.
Het EC werkt samen op het terrein van onderzoek en patiëntenzorg met andere expertisecentra in binnen- en buitenland.
Informatie & communicatie
Het EC fungeert als informatieloket en vraagbaak voor zorgverleners, patiënten en hun naasten.
Het EC draagt zorg voor voorlichting over de (cluster van) zeldzame aandoening(en) aan zorgprofessionals buiten het EC en andere beroepsbeoefenaars buiten de gezondheidszorg.
Onderzoek
Het EC verricht (basaal) wetenschappelijk onderzoek op het gebied van de zeldzame aandoening en publiceert hierover.
Het EC draagt zorg voor dataregistratie van patiënten met de desbetreffende aandoening.
Grensoverschrijdende gezondheidszorg
Het EC coördineert en adviseert, indien nodig, grensoverschrijdende gezondheidszorg met aangewezen EC's in andere EU-landen, waarnaar patiënten of biologische monsters kunnen worden doorverwezen.

BIJLAGE 3: Digitale vragenlijst (kleine wijzigingen onder voorbehoud)

Welcome Sir/Madam,Welcome to the NFU Rare Condition Expertisecenter Survey.

Please fill out your personal info here:

- First name
- Last Name
- Email Address
- Phone number
- At which umc do you work?
- Other health care institution

Of which centre of expertise are you the contactperson?
Assessment number of the EC:

Quality of care

If needed you will be able to insert an extra page for another cluster of rare conditions and/or specific rare condition at the end of this page.

2. Please fill out the first (cluster of) rare disease and corresponding Orphacode
Comments :

Criterium: The EC provides - if relevant for the specific rare condition - highly specialised, complex patient care in the areas of diagnostics, treatment and aftercare, and follow-up.

3. How many patients with the rare condition(s) in question are seen by the members of the multidisciplinary team per year?

- for diagnostics:
- for treatment and aftercare:
- for (long-term) follow-up:
- for a first appointment (if known):
- for second opinion (if known):

What is the prevalence (an estimate of the number of known patients in NL):

4. Is there a minimum number of patients defined by the guideline or standard in order to improve knowledge and experience?

- yes, how many:
- no, there is no guideline and/or standard
- no, the guideline does not mention a minimum number

5. Has the EC established care pathway(s)?

- yes, for diagnosis
- yes, for treatment and aftercare
- yes, for follow-up
- no

6. You answered the previous question with yes, ... please upload the relevant documents: Browse... and upload (max 5 documents).

Criterium: The EC contributes to the development of care standards and guidelines and is involved in their dissemination and implementation, together with representatives from involved patient organisations.

7. Are there guidelines and/or care standards for the rare condition?

- yes, a guideline developed by the centre of expertise
- yes, a guideline developed in cooperation with the patient organisation(s)
- yes, a guideline developed by or in collaboration with another EC or working group in the Netherlands
- yes, a guideline developed abroad:
- yes, a guideline developed in collaboration with other (international) patient organisation(s)
- yes, a care standard developed by the centre of expertise
- yes, a care standard developed in cooperation with the patient organisation(s)
- yes, a patient version of the care standard developed by the centre of expertise
- yes, a patient version of the care standard in cooperation with the patient organisation(s)
- no, but there are currently initiatives for developing a care standard and/or guideline(s) by the centre of expertise
- no, but there are currently initiatives for developing a care standard and/or guideline(s) in cooperation with the patient organisation(s)
- no, there are no initiatives

8. Is the EC involved in updating existing quality standards?

- yes, in cooperation with the patient organisation
- yes, other namely
- no

Criterium: The EC has a system for safeguarding the quality of care.

9. Have quality indicators or criteria been developed specifically for the rare condition in question?

- yes, indicators
- yes, criteria
- yes, developed by the centre of expertise
- yes, in cooperation with the patient organisation
- no, but they are under development

no

10. What does the EC do with this quality information?

- apply the Plan-do-check-act system
- other, namely

10. Do you want to answer these questions again for another condition/cluster?

- yes, I want to answer the above questions again for a second condition or cluster
- no I want to continue to the questions on quality of care on a general level

[*Als u op Yes klikt, kunt u wederom een (cluster van) aandoening(en) selecteren en krijgt u opnieuw de bovenstaande vragen hiervoor. Op deze wijze kunt u dus 10 (clusters) van aandoeningen opvoeren. Klikt u op No, dan gaat u door met de onderstaande vragen*]

Quality of care-general

Criterium: The EC delivers care using a fixed multidisciplinary team (MD team).

12. How many staff members (discipline, number and fte) are directly/permantly involved in the centre?
Upload table of names, specialisms and institution if located elsewhere.
Browse... and upload format 1.

13. The EC has defined the roles within the MD team in the care pathways and informs the patient and involved parties of this:

- yes, defined and provides information
- not defined but the EC does provide information
- no

14. The EC has defined and has informed care providers, patients and their family about the availability of the MD team for emergency/non-emergency care.

- yes
- no

Criterium: The EC coordinates the care provision within the entire chain for the specific condition.

15. The EC has a central care provider/case manager/care coordinator for the entire care pathway

- yes
- yes, but not for all phases of the care pathway
- no, that is up to the treating physician
- no

16. If yes, patient information is shared between/with professionals via:

- letters
- tele-medicine
- tele-expertise (e.g. Google glass)
- other, namely…..

17. If no care pathway is described, which joint venture(s) has the EC established in order to safeguard the entire care chain? (if necessary in the form of shared care)

- Intramural:
- Extramural:

Criterium: Within the EC, there is awareness of and a contribution to the most recent (basic) scientific developments regarding the diagnosis, casual and/or symptomatic treatment and secondary and tertiary preventive measures and/or specific psychosocial support for the patient group in question.

16. How do you keep abreast of the latest scientific developments in the field of diagnosis and/or treatment of the rare condition you are an expert for?

- via articles in scientific journals
- via (inter)national congresses : participation
- via (inter)national congresses : participation as an invited speaker
- via (inter)national congresses : contribution to organising the congress
- via participation in (inter)national committees/working groups
- in a different way than described above, namely ….

17. You answered the previous question with "via participation in (inter)national committees/working groups". Could you please elaborate on this?

- which committees/working groups:
- what does this participation entail?

19. Comments about the theme "Quality of care"?

Transition

Criterium: Where necessary, the EC ensures the continuity of care from childhood, though adolescence and into adulthood (transition care).

20. How is this care transition from pediatric to adult care safeguarded?

- the central care provider organises this
- the treating physician coordinates this
- the parents coordinate this
- Other, namely
- N/A

21. How is the quality of care transition safeguarded?

- there is a quality indicator for transition care
- there is standard information transfer about (the importance of) transitions care for the EC multidisciplinary team
- there is standard information transfer about (the importance of) transitions care for primary care and paramedics, such as:

- there is standard information transfer about (the importance of) transitions care for secondary and third-line care, such as:
- other, namely
- N/A

22. Comments about the theme "Transition"?

Continuity of EC

Criterium: The EC provides training of and/or transfer of knowledge to (new) experts in the MD team.

23. Is an alternate available for each discipline involved in the MD team to safeguard the continuity of the EC in case a member drops out or departs?

- yes, for every discipline
- yes, except for:
- no

24. How does the centre provide training of and/or transfer of knowledge to new experts in the MD team?

- MD meeting (e.g. case presentation)
- education programme (e.g. "refereeravond", CME, ...):
- training on the job
- other, namely:

Criterium: The EC is accredited by the Board of Directors.

25. Is the EC accredited in writing by the Board of Directors of your institution, which thus guarantees continuation of the EC.

- yes
- no

Criterium: The EC is open to auditing.

26. Is the EC open to auditing?

- yes
- no

27. Comments about the theme "Continuity of EC"?

Cooperation with other parties

Criterium: The EC works together with patients and patient organisations in orde to improve care quality.

28. How does your centre maintain contact with the patient organisation(s) in question?

- periodic meetings/alignment with the following patient organisation(s): .
- frequency of periodic meetings/alignments: .
- no contacts with patient organisation(s)
- no group (known)
- other, namely .

29. What activities are undertaken to integrate the patient perspective together with patients/patient organisation(s)?

- consult patients / PO members
- patient information meetings (care professionals and patients together)
- other, namely: .

Criterium: The EC works together with other national and international centres of expertise in the fields of research and patient care.

30. How is this cooperation given form?

for patient care:

- national working group
- international working group
- within ERN
- other, namely.

for research:

- (inter)national projects/consortia
- within ERN
- other, namely .

31. Comments about the theme "Cooperation with other parties"?

Information and communication

Criterium: The EC functions as a point of information for care providers, patients and their family and friends.

- 32. Has the EC provided information regarding availability for care providers and for patient and family and friends?
- yes, to care providers via:
- website(s)
- brochures
- other, namely:.
- yes, to patients and family via:
- website(s)
- brochures

- other, namely:.
- no

33. How often is the centre consulted by other treatment professionals, researchers or patients and family, for example about the diagnosis (second opinion) or treatment (guidelines and new medicines)?
    - less than 10x per year
    - more than 10x per year
    - other, namely (x per year):.

34. Who are you consulted by?
    - intramural medical specialists
    - extramural medical specialists
    - GPs
    - paramedics
    - researchers

35. Where do these parties come from?
    - the Netherlands
    - Europe
    - elsewhere in the world

36. What is the EC consulted for?
    - general information/education about the rare condition
    - diagnostics
    - second opinion
    - treatment advice
    - shared care
    - scientific research

37. Is the EC actively visible?
    - yes, towards primary care providers, by
    - yes, towards secondary care providers, by
    - yes, towards patients and family
    - yes, towards patient organisation(s)
    - yes, towards researchers
    - no

38. Is the accessible information available tailored to the specific needs of patients and their family?
    - yes, had been developed (or is under development)
    - no, but there are initiatives to develop this information
    - no and there are no initiatives to do so

39. If you answered the previous question with "YES". Please elaborate by stating the following.

- The information has been developed…..
- in collaboration with the patient organisation(s)
- for medial matters
- for social matters
- for cultural matters

40. Is there specific information related to cultural issues included in the described care pathway?

- yes
- no
- N/A

Criterium: The centre provides education about the (cluster of) rare condition(s) to care professionals outside the EC and other professionals outside the health care.

39. How does the EC help to increase awareness of the rare condition(s)? By:

- courses/elective during (medical) education
- courses/continuing medical education, namely .
- active awareness raising, namely .
- other, namely .

40. The EC has contact with an awareness raising institution in the field of rare conditions?

- no
- yes
- Erfocentrum
- Orphanet

other, namely: .

41. Comments about the theme "Information & communication"

Research

Criterium: The EC conducts scientific research in the field of the rare condition and publishes on the topic.

44. Is there a professor affiliated with the EC?

- yes, intramurally, name of professor(s):
- yes, extramurally, name of professor(s) and institution:
- no

45. What kind of scientific research is performed on the rare condition within the EC (several answers possible)?

- basic scientific research
- translational research

- clinical research
- clinical (orphan) drug research
- social science research
- other, namely

46. Is the EC aware of (inter)national research initiatives?

- no
- yes
- by keeping up to date on scientific research literature
- as a partner in a (inter)national research project
- as a member of (inter)national committees/working groups
- other, namely

47. How many articles have been published by the EC about the rare condition(s) over the past 5 years?

48. Enclose list of max. 10 of the most relevant publications from the EC in the past 10 years (Including 5-year IF) Browse... and upload format 2.

49. What grant(s) has the EC obtained over the past 5 years? Browse.. and upload format 3.

50. How many employees affiliated with the EC conduct scientific research?
(table with name, function and scope of research appointment) Browse... and upload format 4.

Criterium: The EC provides data registration of patients with the condition in question.

51. Does the EC record data?

- yes, locally, via EHR ("EPD")
- yes, locally, using separate registration system/database
- yes, regionally
- yes, nationally
- yes, internationally
- no
- no, but the following actions have been taken to set up a (inter)national database:

51. If previous question is answered with yes, please upload a list of data that are registered by the EC
Browse... and upload format 5.

52. Is material stored in a biobank?

- yes, namely
- no
- no, but the following actions have been taken to set up a (inter)national biobank:

53. Does the EC manage the national database?

- yes, and the database is aligned to existing registries abroad
- yes, and a procedure for data sharing with others (in NL and abroad) is available
- no, because another EC manages, namely
- no, because there is no national database

54. Comments about the theme "Research"

Cross-border health care

Criterium: The EC coordinates and advises on, if necessary, cross-border health care together with specific ECs in other EU countries where patients or biological samples can be referred to.

52. Does the EC refer patients to accredited ECs in other EU countries?

- yes, how many per year:
- yes, within the context of an ERN
- yes, at the patient's request
- yes, on the initiative of the EC
- no

53. Does the EC receive referred patients from accredited ECs in other EU countries?

- yes, how many per year:
- yes, within the context of an ERN
- yes, at the patient's request
- yes, on the initiative of the foreign EC
- no

54. Does the EC send biological samples to accredited ECs in other EU countries for diagnostic and research purposes?

- yes, how many per year:
- yes, within the context of an ERN
- yes, at the patient's request
- yes, on the initiative of the foreign EC
- no

55. Does the EC receive biological samples for diagnostic and research purposes from accredited ECs in other EU countries?

- yes, how many per year:
- yes, within the context of an ERN
- yes, at the patient's request
- yes, on the initiative of the foreign EC
- no

56. The EC has an eye for and takes cultural differences into account, and ensures/provides equal treatment, regardless of (EU) country of origin, in accordance with national and international ethical and legal frameworks.

- all patients, regardless of the EU country they are from, are seen/treated
- patients from the following member states have been seen by your centre:
- patients from the following member states were not seen after being registered:
- other, namely

57. Comments about the theme "Cross-border health care"

BIJLAGE 4: Formats bij vragenlijst kandidaat ECZA

Format 1: documentation on the multidisciplinary (care) team

Name of UMC:…….

Expertise center:……

Assessment number:…….

The expertise center delivers care with the following fixed multidisciplinary team:

Titel	Name	Specialism/Discipline	If extramural, where?	Fte(*)
	You may add/remove lines			

(*) fte as the time spent on activities for the EC (not total fte of appointment)

Please save this format 1 separately on your computer as a PDF. You will be asked to upload it during the survey.

Format 2: documentation on most relevant scientific research publications

Name of UMC:…….

Expertise center:……

Assessment number:…….

Fill out a maximum of 10 publications for the Expertise Center as a whole. The most relevant publications over the past 10 years are:

	• Titel • Authors (please underline members of your EC) • Journal, year, volume, pages and (5-yrs) impact factor of journal
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	You may remove lines

Please add maximal 3 papers for each specific rare disease for which you which to be assessed seperately. The most relevant publications over the past 10 years are:

	• Titel • Authors (please underline members of your EC) • Journal, year, volume, pages and (5-yrs) impact factor of journal • Concerning the specific rare disease(s):……
1	
2	
3	
	• Titel • Authors (please underline members of your EC)

	• Journal, year, volume, pages and (5-yrs) impact factor of journal • Concerning the specific rare disease(s):……
1	
2	
3	
	• Titel • Authors (please underline members of your EC) • Journal, year, volume, pages and (5-yrs) impact factor of journal • Concerning the specific rare disease(s):……
1	
2	
3	
	You may add or remove lines

Please save this format 2 separately on your computer as a PDF. You will be asked to upload it during the survey.

Format 3: documentation on <u>obtained research grants</u>

Name of UMC:…….

Expertise center:……

Assessment number:…….

Grants obtained over the <u>past 5 years</u> by (members of) the expertise center are:

	• Name of funding body • Titel of project • Year • Amount (€)
1	
2	
3	
4	
5	You may add/remove lines

Please save this format 3 separately on your computer as a PDF. You will be asked to upload it during the survey.

Format 4: documentation on the <u>scientific research team</u>

Name of UMC:…….

Expertise center:……

Assessment number:…….

How many employees affiliated with the expertise center conduct scientific research:

Titel	Name	function	Scope of research	Fte(*)
	You may add/remove lines			

(*) fte as the time spent on activities for the EC (not total fte of appointment)

Please save this format 4 separately on your computer as a PDF. You will be asked to upload it during the survey.

Format 5: documentation on the <u>data registration</u>

Name of UMC:…….

Expertise center:……

Assessment number:…….

Please list below the data that are registered by the expertise center:

Name of databank	Kind of data:	Registered since (year)	Managed by:
	You may add/remove lines		

Please save this format 5 separately on your computer as a PDF. You will be asked to upload it during the survey.