Trial & treatment ready with registries

Call 2026

Prinses Beatrix Spierfonds

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The Prinses Beatrix Spierfonds funds, directs, and stimulates scientific research into neuromuscular diseases. Developments in the field are progressing rapidly. New technologies, innovative treatment methods, and closer collaboration bring us closer to what once seemed unattainable: a future in which everyone with a neuromuscular disease has access to effective treatments. The Prinses Beatrix Spierfonds aims to play a meaningful role in achieving that future by investing in the development of new medicines and rehabilitation in the Netherlands and by ensuring that patients can benefit from international breakthroughs.

Trial & treatment readiness programme

Worldwide, the number of medicines being developed for neuromuscular diseases is increasing at an unprecedented pace. This development offers enormous opportunities for patients. The Spierfonds wants to ensure that people in the Netherlands can benefit as quickly as possible. Through the Trial & treatment readiness programme, we aim to enable more patients in the Netherlands to participate in (inter)national clinical trials testing new medicines and to achieve faster and improved access to effective and affordable therapies.

Call 'Trial & treatment ready with registries'

Part of the Trial & Treatment readiness programme, is the call 'Trial & treatment ready with registries'. Registries are essential for trial and treatment readiness. They ensure that patients are identifiable for research, accelerate clinical trial processes, and help position the Netherlands as an attractive trial location. They also generate crucial natural history data used to assess the effectiveness of new medicines. Additionally, registry data contributes to Health Technology Assessment (HTA) and supports preparation for future treatments by providing insight into how many patients may benefit from a therapy and what clinical capacity or expertise is required.

Goal of the call

The goal of this call is to ensure that the Netherlands has strong, visible registries that contribute to trial and treatment readiness. Depending on the neuromuscular disease, different phases and needs may apply.

Project proposals must have one of these primary objectives:

- **Developing** a new registry for one or more neuromuscular diseases (or adding a disease to an existing registry)
- Expanding an existing registry with **new patients and/or time points**
- Expanding an existing registry with **additional data types** (measurements, questionnaires, etc.) relevant to trial and/or treatment readiness

In addition, applicants may propose one of the following subprojects:

- Data analysis for natural history research
- Data analysis for treatment readiness (e.g., HTA)
- Adapting the registry to allow linkage with other databases (FAIRification)
- Reducing registration burden (automation)

Important criteria

Project applications within this call are assessed on several key criteria:

- **Urgency**: for the disease in question, a registry must be necessary and urgent. There must be potential medicines in the international development pipeline. This means at least one compound in a clinical phase and/or two compounds in preclinical development. Additionally, the registry must not be realistically fundable through other means at this stage.
- **Feasibility**: the proposed number of patients to be registered must be realistic. Furthermore, there must be a plan in place to sustainably continue the registry after project completion, including funding, workload, and integration within the expertise centre.
- **Patient participation**: patient representatives must be involved in all aspects of the registry. This includes determining what is registered, developing questionnaires, and contributing to the governance structure.

Other important elements in the call include:

- Visibility: registries must be visible to Dutch patients and healthcare professionals, and particularly to international partners such as pharmaceutical companies. Scientific publications are important for this purpose; applicants may include open access publication costs in their budget.
- FAIR: registries must be suitable for linkage with other databases. For newly developed registries, it is essential to design them according to FAIR principles from the start.
- Knowledge sharing: many strong registries already exist in the Netherlands. Sharing knowledge and learning from each other is essential to ensure efficient processes.
- Future perspective: not all registries can be fully comprehensive from the beginning, but anticipating future expansion is crucial from the outset.

Procedure

This call uses a two-phase application process consisting of a pre-application stage followed by a full proposal stage for selected applicants. Pre-applications are assessed based on urgency and an initial estimation of feasibility. Spierziekten Centrum Nederland and the patient organisation Spierziekten Nederland advise the Spierfonds on how well each pre-application meets these criteria. Based on this advice, the Spierfonds determines which applicants are invited to submit a full proposal. The aim is to grant more than 40% of fully submitted proposals.

Full project proposals are evaluated by external reviewers for urgency, scientific quality and the strength of the project group. Additionally, the User Committee assesses the societal impact and the extent to which the patient perspective has been incorporated. The assessments from external reviewers and the User Committee are shared anonymously with the applicant, who is invited to respond in writing (rebuttal). Based on all assessments and the applicant's rebuttal, the assessment committee issues recommendations on which applications to fund. In the case of equally suitable proposals, the Spierfonds may apply prioritisation based on policy and strategic relevance to the organisation.

Deadline and budget

Within this call, a budget of €100,000 to €200,000 can be requested. This budget can be supplementary to existing funding; the Spierfonds does not have to be the sole or primary funder of the registry. We would like to be notified if other organisations wish to contribute cofunding to the application.
The requested amount may be allocated between the main objective and any sub-projects as required. We encourage applicants to carefully consider the project's duration, as well as the necessary expertise and staffing. In the application form, we ask you to justify these choices so that it can be assessed whether the proposed duration and staffing are realistic and appropriate.

Timeline

The timeline for this call is as follows:

Submission of pre-application	5 May 2026 at 14:00
Invitation to submit full proposal	First week of June 2026
Submission of full proposal to Spierfonds	4 August 2026 at 14:00
Reviewer assessment	August–September 2026
Rebuttal phase	Deadline mid-October 2026
Assessment meeting	Mid-November 2026
Final decision	Early December 2026

Contact

If you have any questions about this call, we are happy to help. Please contact Simone van den Berge via onderzoek@spierfonds.nl.

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Appendix 1: Conditions

Applications submitted within the 'Trial & treatment ready with registries' call must meet the conditions below to be eligible for assessment. In case of doubt, the Spierfonds reserves the right to decline an application based on advice from the Chair of the Scientific Advisory Board. Applicants will be notified within six weeks after the submission deadline.

The applicant

- Must hold a PhD and have (or receive) an appointment at the institution where the project will primarily be carried out, which must be a national Centre of Expertise for neuromuscular diseases as recognised by the Ministry of VWS.
- May submit only one application as principal investigator within this call.
- Serves as the official contact person for the Spierfonds throughout the process.

Project scope

- The project must concern one or more neuromuscular diseases listed in appendix III.
- If the project concerns a very rare disorder (fewer than 40 patients in the Netherlands), the application must justify why a registry is needed for such a small population.

The project

- The project must be carried out primarily in the Netherlands. If any component takes place abroad, a clear justification must be submitted to the Spierfonds in advance..

The proposal

- The (pre-)application must be written in clear and understandable English. The full application must also include an accessible Dutch public summary.
- Any applications for external funding related to the same project must be disclosed along with their outcomes.

Funding regulations

- Applicants must comply with the Spierfonds Regeling Subsidieverlening when preparing the budget, except for the minimum 0.5 FTE requirement for scientific staff.
- If granted, the Algemene Subsidievoorwaarden of the Spierfonds apply.

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Appendix 11 – Assessment Procedure call 'Trial & treatment ready with registries'

Assessment of pre-applications

Pre-applications that meet the requirements outlined in Appendix I are assessed for urgency and a preliminary evaluation of feasibility. Spierziekten Centrum Nederland and the patient organisation Spierziekten Nederland advise the Spierfonds on these criteria. The Spierfonds will decide – based on this advice – whether a full application may be submitted. We aim for a funding rate of at least 40%. Applicants will be informed whether they may submit a full application and if so, receive additional instructions.

Assessment of full applications and rebuttal

Full proposals are reviewed by at least two external experts (reviewers) and at least two members of the User Committee. Reviewers assess the following criteria:

- Scientific quality and feasibility
- Urgency
- Quality of the project group

The User Committee assesses from the patient perspective:

- Societal relevance
- Meaningful patient involvement

Both reviewers and User Committee members provide their justified assessment anonymously, using the designated assessment form. These anonymous assessments are submitted to the applicants for rebuttal. Assessments without a substantive justification will be excluded from the rest of the procedure.

Conditions for reviewers

Reviewers are non-interested parties to a grant application. The reviewer and the applicant may not have co-authored publications in the last three years. Reviewers are selected internationally, through suggestions from the applicants and online databases. A list of external reviewers from previous years who have provided well-reasoned assessments is also used.

Preliminary review and assessment meeting

The Spierfonds assigns the grant applications, along with the reviewer reports and the applicants' responses, to the pre-assessors (members of the Scientific Advisory Board (SAB)). Each application is pre-assessed by at least two members of the SAB. The pre-assessment is carried out by SAB members who have no conflict of interest with regard to a grant application. In this, the SAB operates in accordance with the Spierfonds' Gedragscode Belangenverstrengeling on conflicts of interest.

Based on the reviewer assessments and the rebuttal, the pre-assessors conduct a preliminary assessment of the grant applications assigned to them. The pre-assessors provide a more detached judgement than the reviewers and calibrate the reviewer comments and rebuttals

for all applications under consideration. The pre-assessors are not intended to take over the role of the reviewers or to duplicate their work. Therefore, the pre-assessors are not meant to introduce new arguments after the rebuttal stage. This should only occur if compelling arguments are involved.

Content of the preliminary assessment

The preliminary assessment is a written preparation for the plenary assessment meeting. The pre-assessors provide their independent individual judgement regarding:

- The quality of each of the reviewer reports.
- The quality of the grant application, the impact and urgency of the subject, and the quality of the applicant, based on the rebuttal.
- A final recommendation on the quality, impact, and urgency of the application.

In the preliminary assessment, it is possible to deviate from the judgement of the external reviewers based on the applicant's response. Additionally, some of a reviewer's arguments may be weighted differently, or in the event of discrepancies between reviewers, the judgement of one reviewer may be given more weight. In the preliminary assessment, any deviations from the reviewer judgements must be well-justified. The pre-assessor has the option to exclude a reviewer if the quality of their report is insufficient. In this case, the Spierfonds will not include this reviewer's score and will correct the average reviewer score. The pre-assessors complete the preliminary assessment forms independently of each other. These are sent to the Research & Innovation department prior to the assessment meeting.

Preparation for the assessment meeting

For the final recommendation, an assessment committee is formed, including members of the SAB and patients (or patient representatives), possibly supplemented with external expertise. The Research & Innovation department creates a score list of the project applications, containing the scores from the external reviewers and the pre-assessors. This list, along with the applications and assessments, is sent to all members of the assessment committee in preparation for the meeting. Based on this, the assessment committee provides a recommendation on funding to the Supervisory Board and the Board of Directors of the Spierfonds.

Funding / rejection

Based on the proposal for awarding and rejecting applications and the available budget, the Supervisory Board and the Board of Directors of the Spierfonds will decide which project applications are eligible for funding and which will be rejected. In the event of equal suitability, the fund may prioritise applications based on the policy and interests of the Spierfonds.

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Appendix III: Neuromuscular disorders

Motor neuron diseases
- Amyotrophic lateral sclerosis (ALS)
- Polio and post-polio syndrome (PPS)
- Primary lateral sclerosis (PLS)
- Progressive spinal muscle atrophy (PSMA)
- Spinal-bulbar muscular atrophy (SBMA)
- Spinal muscular atrophy (SMA)

Peripheral nerve diseases
- Charcot Marie Tooth (CMT / HMSN)
- Chronic idiopathic axonal polyneuropathy (CIAP)
- Hereditary neuropathy with pressure palsies (HNPP)
- Small fiber neuropathy

Inflammatory neuropathies
- Chronic inflammatory demyelinating polyneuropathy (CIDP)
- Guillain-Barré syndrome (GBS)
- MGUS polyneuropathy
- Multifocal motor neuropathy (MMN)
- Neuralgic amyotrophy (NA)

Neuromuscular junction diseases
- Congenital myasthenic syndromes
- Lambert-Eaton myasthenic syndrome (LEMS)
- Myasthenia gravis (MG)

Muscular dystrophies
- Becker muscular dystrophy (BMD)
- Duchenne muscular dystrophy (DMD)
- Emery-Dreifuss muscular dystrophy (EDMD)
- Facioscapulohumeral muscular dystrophy (FSHD)
- Limb-girdle muscular dystrophies (LGMD)
- Oculopharyngeal muscular dystrophy (OPMD)
- Congenital muscular dystrophies (merosin-deficient, Ullrich, dystroglycanopathy, integrin-deficient, rigid spine)

Myotonic disorders
- Myotonic dystrophy (DM)
- Non-dystrophic myotonias (Thomsen, Becker, Paramyotonia Congenita)
- Periodic paralysis (PP)

Congenital myopathies
- Brody myopathy
- Central core disease
- Myotubular myopathy/centronuclear myopathy
- Nemaline myopathy
- Distal myopathies (Miyoshi, Nonaka, Welander, Markesbery, Laing)

Inflammatory myopathies
- Dermatomyositis
- Inclusion body myositis (IBM)
- Polymyositis

Metabolic myopathies
- Glycogen storage diseases
- Lipid storage myopathies
- Mitochondrial myopathies

- Of the infectious diseases, only acute anterior poliomyelitis is eligible for funding.
- Not eligible for funding are research into diseases resulting from trauma, diabetes mellitus, cardiovascular abnormalities, cancer, drug use, or intoxications (alcohol); diseases that are manifestations of a mental illness or disorder; unexplained conditions without an organic substrate.
- For multisystem diseases, the grant application must demonstrate that it primarily presents a neuromuscular phenotype with muscle weakness at the forefront.