



ENDOMETRIOSE - VEREINIGUNG  
DEUTSCHLAND E. V.

## ENDOMETRIOSIS IS EUROPEAN!

### A POSITION PAPER OF THE ENDOMETRIOSIS ASSOCIATION GERMANY ON THE EUROPEAN ELECTIONS 2024 AND AN APPEAL FOR A EURO- PEAN ENDOMETRIOSIS STRATEGY

In view of the prevalence and severity of the disease endometriosis and in view of the elections on June 9, 2024, the European Union should take a united approach and present a **European Strategy for Endometriosis** that covers the areas of education, care, causal research, work and social affairs. This position paper is intended to serve as the basis for such a strategy and consists of ten concrete starting points to improve the care situation for those affected in a sustainable, long-term and effective manner. Die Mitgliedstaaten der Europäischen Union sollten daher die Erfahrungen der letzten Jahre nutzen, den Austausch untereinander suchen und gemeinsam daran arbeiten, die Versorgungslage für alle Endometriose-Betroffenen in der Union zu verbessern.

Leipzig, February 2024

Endometriose-Vereinigung Deutschland e.V.<sup>1</sup>

Sarah Kube  
Chairman

Maria Bambeck  
Deputy Chairman

Michelle Röhrig  
Chief Financial Officer

Endometriose-Vereinigung Deutschland e.V.  
Bernhard-Görling-Straße 152  
04277 Leipzig  
Tel.: 0341 3065305  
Fax: 0341 3065303  
E-Mail: [info@endometriose-vereinigung.de](mailto:info@endometriose-vereinigung.de)  
[www.endometriose-vereinigung.de](http://www.endometriose-vereinigung.de)



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<sup>1</sup> The Endometriose-Vereinigung Deutschland e.V. founded in 1996, is a nationwide self-help organization by and for those affected by endometriosis. Our association has over 3,000 members. Our core tasks are to educate and provide information about endometriosis, to advise those affected by endometriosis and to strengthen the position of patients in politics and society.



## TEN CONCRETE STARTING POINTS FOR A EUROPEAN STRATEGY FOR ENDOMETRIOSIS

- (1) Europe-wide awareness campaign on endometriosis and menstrual pain
- (2) Establishment of an Inter-Speciality Endometriosis Program
- (3) Development of a European Endometriosis Information System (EEIS) eines „European
- (4) Supporting Member States in the development of national endometriosis strategies
- (5) Regular EU reporting on the situation of those affected and introduction of ECHI indicators for endometriosis
- (6) Mandatory information on menstrual cramps when purchasing menstrual products
- (7) Pilot project to raise awareness of endometriosis and menstrual problems as part of youth health check-ups
- (8) Conception of an EU: Safe Menstruation in Schools Scheme
- (9) Global Action Plan: Advancing endometriosis within the WHO
- (10) International Endometriosis Conference with stakeholders from politics, administration, medicine and patient representatives

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### **(1) Europe-wide awareness campaign on endometriosis and menstrual pain**

The trivialization and stigmatization of menstrual pain in society leads to psychological stress, unjustifiably long diagnosis periods and delayed treatment for endometriosis patients. These cause and exacerbate stressful factors in the social and working environment. In our opinion, it is inconceivable that girls and young women are still told that menstrual pain is normal and nothing to worry about, while at the same time for any other type of recurring pain a medical consultation is recommended.

*We therefore recommend the European Union to set up a Europe-wide awareness campaign on endometriosis. On the one hand, the campaign should provide information about the prevalence and severity of the disease. On the other hand, the same campaign will provide effective information about severe menstrual pain.*

*With the experiences of the member states, low-threshold and multilingual educational material is to be created which can be used by the member states in their own local campaigns.*

*As part of the awareness campaign, drugstores, pharmacies, clinics and specialist practices (especially gynecological practices) are to be encouraged to use the educational material and make it publicly available.*

*In the first week of March, a "European Endometriosis Week" is to be held annually with events (online and offline), interview formats, panel discussions, social media content, campaigns and reporting in analog media to draw attention to the situation of those affected and the spread of the disease.*

*When designing and implementing the campaign, representatives of those affected in the member states and medical associations should be consulted. The implementation of events should be financially supported by suitable funding programs.*

### **(2) Establishment of an Inter-Speciality Endometriosis Program**

Healthcare professionals are one of the most important points of contact for chronically ill people. They are in contact with those affected at various points during the course of their illness and over several years. Specialists, especially gynecologists, play an important role in the diagnosis and treat-



ment of the disease. However, due to the variety of non-specific symptoms of endometriosis it is important that, in addition to gynecologists, representatives of other specialist fields such as reproductive medicine, gastroenterology, pediatrics, urology, orthopedics, angiology and occupational medicine are also informed about endometriosis. Pediatricians, general practitioners and school doctors are important contacts for minors, psychologists and psychotherapists are essential for treating the psychological effects of endometriosis, and emergency doctors are relevant practitioners in acute situations. Pharmacists and pharmacy assistants also play an important role in providing access to medication and painkillers. They all need to be informed about the symptoms so that they can act quickly and competently.

Endometriosis patients are therefore dependent on healthcare professionals from various disciplines being effectively educated about the disease and informed about treatment and diagnostic methods.

*We therefore recommend the European Union to promote the establishment of an Inter-Speciality Endometriosis Training Program as part of the EU4Health program and within the framework of a European Endometriosis Strategy. The program should be based on the EU's experience with the Inter-Speciality Cancer Training Program.*

### **(3) Development of a European Endometriosis Information System (EEIS)**

The nationwide cancer registry has proven to be a successful concept for exchanging information about the complex clinical picture of the disease and contributes to improving patient care in Germany. To the same extent, the European Cancer Information System also serves to pool and exchange data from the national registries of the member states.

A similar registry for endometriosis at European level would provide researchers and decision-makers with the necessary data and identify policy options to optimize the care situation and uncover regional differences.

*We therefore recommend the creation of a European endometriosis information system, that serves to monitor the care situation of endometriosis patients and to centrally collect data on endometriosis care and support as part of regular health reporting by all member states.*

*The data will be evaluated as part of regular health reporting on the care situation of endometriosis patients and will serve as a basis for further political measures. The development should be in line with the European Health Data Space initiative and make effective use of existing resources and infrastructure. The data will be made available to the general public through a digital platform.*

### **(4) Supporting Member States in the development of national endometriosis strategies**

Endometriosis is the second most common gynecological disease and affects 10.5 million people in the European Union: the economic damage in nine European countries amounts to around 77.46 billion euros per year.<sup>2</sup> This shows that endometriosis is not only a burden for individuals, but that the negative consequences of the disease have a social impact that is also associated with considerable economic damage.

Despite all this, France is currently the only country in the European Union to have adopted a national strategy for endometriosis. The significant regional differences in care and education systems as well as socio-cultural differences between the 27 Member States of the European Union mean that a national endometriosis strategy is needed for each Member State in the EU in the medium term in order to effectively improve the care situation. A purely European strategy without action by the Member

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<sup>2</sup> Franklin,P. ,Bambra, C. , Albani,V.: Gender Equality and health in the EU, 2021



States would have to be limited to short-term awareness-raising campaigns without far-reaching and long-term changes.

*We therefore recommend the European Union to call on the Member States to develop national endometriosis strategies as part of a European endometriosis strategy and to support them in implementing the strategies as far as possible. Where possible, national strategies should be equipped with measurable target indicators. The European Union should promote scientific and political exchange on effective and non-effective measures between the Member States.*

#### **(5) Regular EU reporting on the situation of those affected and introduction of ECHI indicators for endometriosis**

Although endometriosis is the second most common gynecological disease, there is comparatively little data that provides information on the exact care situation of those affected. For example, it is still unclear why exactly the diagnosis periods in Germany alone are between six and ten years. It is obvious that the care of the 10.5 million people affected by endometriosis can only really be improved if it is clarified where the care deficits come from, how pronounced they are and whether political measures in the past have actually led to an improvement in care.

*We therefore recommend the European Union to compile regular reports on the situation of endometriosis patients and to communicate proposals for action to the Member States on the basis of the available data. The data on the care situation of those affected should be provided by the Member States and they should also be encouraged to formulate their own reports on the situation of those affected.*

*In addition, the European Core Health Indicators are to be revised in consultation with patient associations and medical associations and include indicators as Health State Indicators under the item "Endometriosis: Self-reported prevalence" that covers the following aspects: Frequency of endometriosis, diagnosis period, rate of infertility in the group of endometriosis patients.*

#### **(6) Mandatory information on menstrual cramps when purchasing menstrual products**

Severe pain during menstruation must be clarified with a specialist. This principle is essentially self-evident, but is far from being accepted by society as a whole. Severe menstrual cramps are often denied, ignored or trivialized by the social environment and dismissed as a minor or tolerable inconvenience. This makes it all the more important to convey to those affected, who are sometimes in great pain and can only go about their work and everyday life by taking strong painkillers, that this pain is not normal and must indeed be clarified with a specialist. At this point, the manufacturers of menstrual products also have a special responsibility and can use their market power to provide effective information about menstrual pain.

*With this in mind, we recommend clearly visible and easy-to-understand instructions on packaging of menstrual products, informing customers that a medical specialist should be consulted in case of severe menstrual pain.*

*The products could include, amongst others, tampons, sanitary pads, menstrual cups, digital and analog menstrual cycle trackers, panty liners, period underwear, soft cups and menstrual sponges, as well as products that are sold and marketed specifically to relieve menstrual pain, e.g. some TENS machines. In addition, the information should be designed in consultation with the manufacturers of the products and patient association.*



## **(7) Pilot project to raise awareness of endometriosis and menstrual problems as part of youth health check-ups**

One of the biggest problems about the care of endometriosis patients are the unreasonably long diagnosis periods. Especially when there is an initial contact with specialists in adolescence as part of the adolescent health check-up, this opportunity should be used to provide information about the disease and severe menstrual symptoms at an early stage.

*We therefore recommend the European Union to develop guidelines as part of a pilot project together with affected women's associations, medical associations (of gynecologists and pediatricians) and educators, which can serve as a basis for education about heavy menstrual pain and endometriosis as part of adolescent health check-ups in the Member States.*

*The European Union should encourage Member States that do not currently have structured adolescent health check-ups to develop structured and free adolescent health check-ups that benefit from the best practices of Member States.*

## **(8) Conception of an EU: Safe Menstruation in Schools Scheme**

Due to the severity of its symptoms, endometriosis affects those affected not only in their working lives but also in their educational opportunities. It is therefore not only essential that schools provide information about menstrual problems and endometriosis as part of sex education, but also offer a place that supports those affected.

The European Union has ensured that children and young people are provided with high-quality food through nutritional policies such as the EU School Fruit, Vegetable and Milk Program.

*With this in mind, we recommend the European Union to establish an "EU: Safe Menstruation in Schools Scheme" to create medically appropriate conditions in European schools. The scheme should provide funds to enable access to free menstrual products such as tampons, panty liners, pads and menstrual cups in schools, as already being implemented in Scotland in 2021<sup>3</sup>. In addition, the scheme aims to ensure that school teachers are made aware of severe menstrual cramps and are familiar with common conditions such as endometriosis.*

*The program also aims to support schools in teaching about menstrual pain and endometriosis as part of sex education (or at another appropriate point in the curriculum), promote the exchange of curricula between Member States and provide financial support to Member States to develop school materials on endometriosis and menstrual pain.*

## **(9) Global Action Plan: Advancing endometriosis within the WHO**

In addition to improving the care situation for the 10.5 million people affected within the EU, another priority is to improve the care situation for the 190 million people affected worldwide and to establish international cooperation in order to also specifically advance research into the causes. Within the WHO, both the EU and France, which is the second country in the world to adopt a National Endometriosis Strategy in 2022, have influence here: the EU through its 27 Member States and through its strategic partnership with the WHO, France through its membership of the current Executive Board of the World Health Assembly.

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<sup>3</sup> <https://www.tagesschau.de/ausland/europa/tampons-schottland-kostenlos-gesetz-101.html>



*For this reason, we recommend the European Union, its Member States and the European Commission to advocate both within the WHO and in the strategic partnership between the EU and the WHO for the development of a Global Action Plan on Endometriosis.*

#### **(10) International Endometriosis Conference with stakeholders from politics, administration, medicine and patient representatives**

Endometriosis is European: the disease threatens the earning capacity, quality of life and reproductive freedom of 10.5 million people within the EU. But endometriosis is also a multi-layered political issue: in addition to clear health policy aspects, educational, research and social policy dimensions must also be taken into account. A long-term improvement in care can only be guaranteed if a broad alliance of politicians, administrators, doctors and patient associations stand behind the project.

In view of the high prevalence of the disease and its profound and serious consequences for the lives of millions of people affected in the EU, the European Union should structure this alliance.

*We therefore recommend the European Union to hold an International Endometriosis Conference with stakeholders from politics, administration, medicine and patient representatives.*

*In particular, the WHO, the European Endometriosis League, European Society of Gynecological Endoscopy, International Society for Ultrasound in Gynecology and Obstetrics, International Society of Gynecological Endoscopy, European Society of Human Reproduction and Embryology, International Diagnosis Group Endometriosis and Adenomyosis and the member associations of the European Endometriosis League should also take part in the conference.*

*Following the example of the Saint Vincent Declaration in 1989, the conference will present a final declaration with clear goals for improving the care of endometriosis patients and form the start of the conception of the European Endometriosis Strategy.*

#### **Responsible for the content within the Endometriose-Vereinigung Deutschland e.V. and contact persons:**

Anja Moritz  
Javed Lindner  
Verena Fisch

More about the political work of Endometriose-Vereinigung Deutschland e.V.  
<https://www.endometriose-vereinigung.de/auf-bundesebene/>