

# Joint Declaration and Agreement on the Establishment of the National Action League for People with Rare Diseases

*(Nationales Aktionsbündnis für Menschen mit Seltene Erkrankungen - NAMSE)*

Approximately 7,000 to 8,000 out of the ca. 30,000 known diseases are classified as rare diseases. In the European Union, a disease is deemed to be rare if it affects not more than 5 out of 10,000 persons in the EU. An estimated 4 million people suffer from a rare disease in Germany, and approx. 30 million throughout the European Union.

It is the rarity of the individual diseases that renders research and the medical care of those affected difficult for both medical and economic reasons. Therefore, the diagnosis and therapy of these diseases are fraught with particular challenges.

In Germany's pluralistically structured health care system that is characterised by diverse levels of competencies, long-term improvements in the prevention, diagnosis and therapy of rare diseases can only be accomplished if we succeed in assembling initiatives and making all actors involved cooperate in a coordinated and goal-oriented manner that consistently puts patients' care needs first.

The parties to this agreement support the initiative for the formation of a National Action League for People with Rare Diseases. They share the opinion that joint action can create the prerequisites for an enhancement of the health situation of people with rare diseases that is effective over the long term. They declare their willingness to contribute towards the implementation of the established goals through their active participation in the **Action League**.

The Action League shall contribute to implementing the Recommendation of the Council of the European Union. This includes:

- drafting a National Action Plan for Rare Diseases,
- implementing and monitoring this Plan,
- supporting the establishment of centres of excellence.

The Action League is intended to coordinate measures for improving the health situation of persons with rare diseases and initiate pilot projects and further action in the field of rare diseases.

The Action League works to the following principles:

- It does not pursue any economic interests.

- The Action League works from a patient-centred approach. The patients and their concerns are paramount for the activities of the Action League.
- The specific requirements involved in rare diseases are taken into consideration.
- The Action League is expected to work in an efficient and transparent manner.

**With the adoption of this Joint Declaration, the partners in the Action League document their commitment to achieving the goals established and the implementation measures by means of their active participation. The following are the partners in alphabetical order:**

*ACHSE e.V.  
Allianz chronischer seltener Erkrankungen  
(Alliance for Chronic Rare Diseases)*

*Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG)  
vertreten durch Niedersächsisches Ministerium für Soziales, Frauen, Familie und Gesundheit  
(Working group of the highest health authorities of the Federal Laender, represented by the Ministry for Social Affairs, Women, Family Affairs and Health of the Land of Lower Saxony)*

*Arbeitsgemeinschaft der wissenschaftlichen medizinischen Fachgesellschaften (AWMF)  
(Association of the Scientific Medical Societies)*

*Beauftragter der Bundesregierung für die Belange der Patientinnen und Patienten  
(German Federal Government Commissioner for Patients' Affairs)*

*Bundesarbeitsgemeinschaft Selbsthilfe von Menschen mit Behinderung und chronischer Erkrankung und ihren Angehörigen e. V. (BAG SELBSTHILFE e. V.)  
(Federal Association of Self-help Organizations of People with Disabilities and Chronically Ill People and Their Relatives in Germany)*

*Bundesärztekammer  
(German Medical Association)*

*Bundesministerium für Arbeit und Soziales  
(Federal Ministry of Labour and Social Affairs)*

*Bundesministerium für Bildung und Forschung  
(Federal Ministry of Education and Research)*

*Bundesministerium für Familie, Senioren, Frauen und Jugend  
(Federal Ministry for Family Affairs, Senior Citizens, Women and Youth)*

*Bundesministerium für Gesundheit*  
(Federal Ministry of Health)

*Bundespsychotherapeutenkammer*  
(Federal Association of Psychotherapists)

*Bundesverband der Pharmazeutischen Industrie e. V. (BPI)*  
(Federal Association of the German Pharmaceutical Industry)

*Bundesverband Medizintechnologie e.V.*  
(German Medical Technology Association)

*Bundeszahnärztekammer*  
(German Dental Association)

*Deutsche Forschungsgemeinschaft*  
(German Research Foundation)

*Deutsche Krankenhausgesellschaft e.V.*  
(German Hospital Society)

*Deutscher Pflegerat e.V.*  
(German Council of Nursing)

*Gemeinsamer Bundesausschuss*  
(Joint Federal Committee)

*GKV-Spitzenverband*  
(Umbrella association of German health insurance funds)

*Kassenärztliche Bundesvereinigung*  
(Federal Association of Panel Doctors)

*Kassenzahnärztliche Bundesvereinigung*  
(Federal Association of Panel Dentists)

*Orphanet-Deutschland*  
(The Portal for Rare Diseases and Orphan Drugs Germany)

*PKV Verband der privaten Krankenversicherung e. V.*  
(German Association of Private Health Insurance Funds)

*Verband der Diagnostica-Industrie e.V. (VDGH)*  
(German Association of Diagnostics Industry)

*Verband der forschenden Pharmaunternehmen - vfa bio*  
(German Association of Research-based Pharmaceutical Companies)

*Verband der Universitätsklinika Deutschlands e.V. (VUD)*  
(Association of German University Hospitals)