

RESEARCH FOR RARE DISEASES

Together toward Diagnosis and Treatment

Rare diseases are not so rare: It is estimated that there are approximately 7000-8000 rare diseases. Their prevalence however varies greatly and more than 4 million people in Germany alone are affected.

People with rare diseases have a lot in common: The path to diagnosis is often long and difficult. Once a diagnosis had been made, suitable treatments are rarely available and many patients face chronic suffering and early death. Most rare diseases are caused by genetic mutation and present themselves early in life.

The German Ministry for Education and Research has supported research activities devoted to rare diseases since 2003. Researchers from all over Germany have joined together to investigate certain disease groups. Currently, 10 such networks are being funded.

The aim of the research networks, in which both researchers and medical specialists are involved, is to find the underlying causes of currently incurable diseases and to explore and develop new



therapeutic approaches. The latest technologies such as next generation sequencing for genome research are available.

Close cooperation of research networks located all over Germany and specialised centers for rare diseases allows for the integration of research results into patient care. The networks also cooperate with patient advocacy groups, who bring their expertise to the table.

For more information please visit our website:
www.research4rare.de



NETWORKS AT A GLANCE

AUTOINFLAMMATORY DISORDERS IN CHILDREN AND ADOLESCENTS (AID-NET)

Prof. Dr. Johannes Roth, University Hospital Münster

COGNITIVE IMPAIRMENT DISORDERS WITH DEFECTIVE CHROMATIN (CHROMATIN-NET)

Prof. Dr. André Reis, University Hospital Erlangen

CHARCOT-MARIE-TOOTH DISEASE (CMT-NET)

Prof. Dr. Michael Sereda, University Medical Centre Göttingen

NEURONAL CEROID LIPOFUSCINOSES (NCL2TREAT)

Prof. Dr. Thomas Braulke, University Medical Center Hamburg-Eppendorf

NETWORK OF EARLY ONSET CYSTIC KIDNEY DISEASE (NEOCYST)

Prof. Dr. Martin Konrad, University Hospital Münster

PRIMARY IMMUNODEFICIENCY DISORDERS (PID-NET)

Prof. Dr. Christoph Klein, University Hospital Munich

DYSTONIAS (DysTract)

PD Dr. Jens Volkmann, University Hospital Würzburg

SPEED TRANSLATION-ORIENTED PROGRESS TO TREAT FSGS (STOP-FSGS)

Professor Dr. Marcus J. Moeller, University of Aachen

IMPRINTING DISEASES (Imprinting)

Prof. Dr. Bernhard Horsthemke, University Hospital Essen

RASOPATHIES (GeNeRare)

Prof. Dr. Martin Zenker, University Hospital Magdeburg



RESEARCH **FOR** RARE

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