

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, 12 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

RARE PULMONARY DISEASES (CARPuD 2)

Prof. Dr. Ulrich Martin, Hannover Medical School

CRANIOFACIAL DISORDERS (FACE)

Prof. Dr. Bernhard Zabel, University Hospital Freiburg

GENETIC MODIFICATION OF THE CFTR-GENE FOR CYSTIC FIBROSIS (GALENUS)

Prof. Dr. Joseph Rosenecker, University Hospital Munich

MOTONEURON DISEASES (MNDnet)

Prof. Dr. Albert Ludolph, University Hospital Ulm

IMPRINTING DISEASES (Imprinting)

Prof. Dr. Bernhard Horsthemke, University Hospital Essen

PRIMARY IMMUNDEFICIENCY DISORDERS (PID-NET)

Prof. Dr. Christoph Klein, University Hospital Munich

TRANSLATIONAL NETWORK FOR SARCOMA (TranSaRNet)

Prof. Dr. Heribert Jürgens, University Hospital Münster

SYSTEMIC AMYLOID LIGHT-CHAIN (AL) AMYLOIDOSIS (GERAMY)

PD Dr. Stefan Schönland, University Hospital Heidelberg

HEREDITARY RETINAL DISORDERS (HOPE)

Prof. Dr. Bernd Wissinger, University Hospital Tübingen

NEUROLOGICAL AND OPHTHALMOLOGICAL ION CHANNEL DISORDERS (IonNeurONet)

Prof. Dr. med. Holger Lerche, University Hospital Tübingen

MITOCHONDRIAL DISEASES (mitoNET)

Prof. Dr. Thomas Klopstock, University Hospital Munich



RESEARCH **FOR** RARE

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