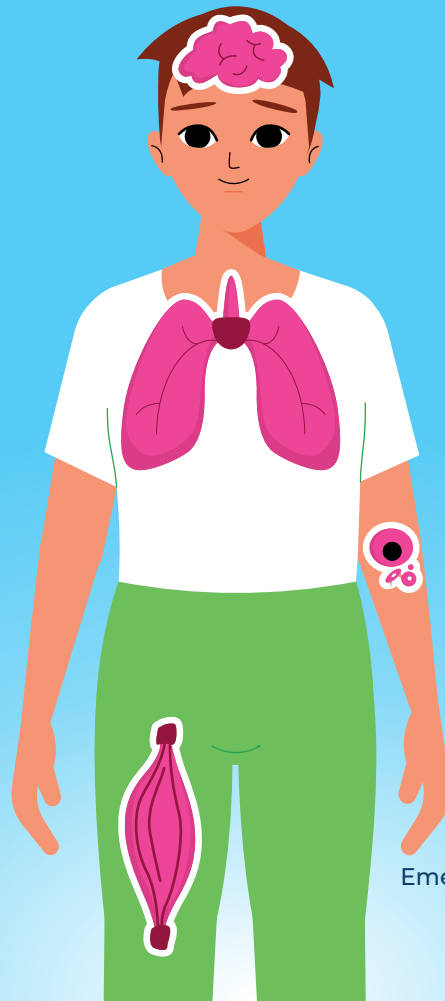


FINDING OUT MORE ABOUT RARE DISEASES

In Europe, a disease is considered rare when it affects less than **1 in 2,000 people**.
Most diseases are severe, chronic, progressive and disabling.

RARE DISEASES HAVE AN IMPACT ON



UNDERSTANDING

Fragile X syndrome
Cri du chat syndrome
Angelman syndrome
Williams-Beuren syndrome

VISION

Retinitis pigmentosa
Stargardt disease
Retinoblastoma
Leber optic neuropathy
Keratoconus

BREATHING

Cystic fibrosis
Alpha-1 antitrypsin deficiency
Primary ciliary dyskinesia
Lymphangiomyomatosis
Idiopathic pulmonary fibrosis

IMMUNE DEFENCE

Wiskott-Aldrich syndrome
Chronic granulomatosis

OTHER BODILY FUNCTIONS

Marfan syndrome
Achondroplasia
Mucopolysaccharidosis
Huntington chorea
Hemophilia
Porphyria

MOBILITY

Duchenne muscular dystrophy
Amyotrophic lateral sclerosis
Steinert disease
Emery-Dreyfuss muscular dystrophy
Pompe disease

ASSOCIATED ISSUES

- Recognition of the disease
- Innovation, research and treatment options
- Access to specialized medical facilities
- Insurance reimbursement and invalidity insurance cover
- Difficulties integrating school and work
- Isolation and access to psychosocial support

>7000

RARE DISEASES

95%

WITHOUT SPECIFIC TREATMENT

80%

GENETIC IN ORIGIN

>50%

ONSET IN CHILDHOOD


1 IN 14 PEOPLE AFFECTED

WORLDWIDE: 300 000 000
EUROPE: 30 000 000
SWITZERLAND: 580 000

More information



Rare diseases in Switzerland and the national concept:

With the aim of improving care for people with rare diseases throughout their care pathway, a series of practical measures have been implemented since 2014 as part of the national rare diseases concept.

A collaboration between:



and the recognized Swiss Rare Disease Centres (Aarau, Basel, Bern, Geneva, Lausanne, Lucerne, Eastern Switzerland, Ticino, Zurich).

More information



WHAT IF IT WAS A RARE DISEASE?

Do you or someone close to you suffer from a rare disease?

Do you think you suffer from a rare disease, but don't have a diagnosis?

Are you looking for support and/or information?

THE RARE DISEASE CENTRES AND THEIR HELPLINES ARE THERE TO HELP YOU:

BASEL - AARGAU - LUCERNE

(DE/EN)
Helpline: 061 704 10 40
Mon - Th 09-12 / 14-17
E-Mail: rarediseasesbasel@ukbb.ch

ZÜRICH - ST. GALL - GRISONS

(DE/EN)
Helpline: 044 266 35 35
Tu 09-11 and Th 14-16
E-Mail: selten@kispi.uzh.ch

ROMANDIE

(FR/EN/IT)
Helpline: 0848 314 372
Mon, Tu, Th, Fr 09-12 / 14-16
E-Mail: contact@infomaladiesrares.ch

BERNE

(DE/FR/EN)
Helpline: 031 664 07 77
Mon - Fr 08-12 / 14-17
E-Mail: rare@insel.ch

TESSIN

(IT/FR/DE)
Helpline: 091 811 88 96 - 079 129 90 59
E-Mail: centromalattierare@eoc.ch
info@malattierare.ch



OTHER SWISS AND INTERNATIONAL SUPPORT STRUCTURES :



Realized with the support of:

