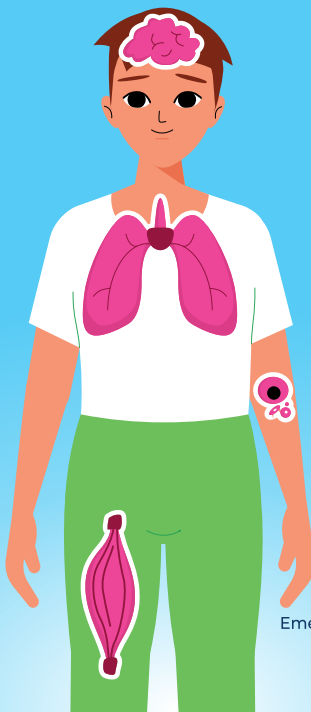


# FINDING OUT MORE ABOUT RARE DISEASES

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

### BREATHING



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

### OTHER BODILY FUNCTIONS



Marfan syndrome  
Achondroplasia  
Mucopolysaccharidosis  
Huntington chorea  
Hemophilia  
Porphyria

### VISION



Retinitis pigmentosa  
Stargardt disease  
Retinoblastoma  
Leber optic neuropathy  
Keratoconus

### IMMUNE DEFENCE



Wiskott-Aldrich syndrome  
Chronic granulomatosis

### MOBILITY



Duchenne muscular dystrophy  
Amyotrophic lateral sclerosis  
Steinert disease  
Emery-Dreifuss 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 cover.

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](mailto:rarediseasesbasel@ukbb.ch)

## ZÜRICH - ST. GALL - GRISONS

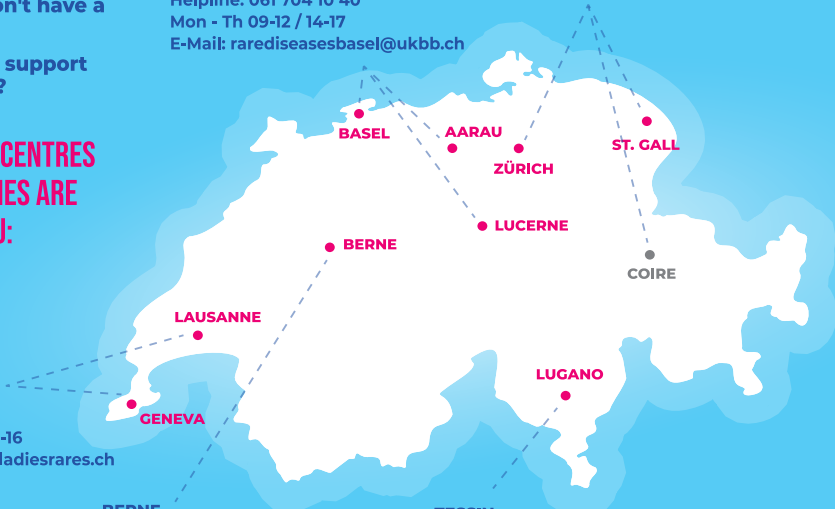
(DE/EN)  
Helpline: 044 266 35 35  
Tu 09-11 and Th 14-16  
E-Mail: [selten@kispi.uzh.ch](mailto:selten@kispi.uzh.ch)

## ROMANDIE

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

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

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



## OTHER SWISS AND INTERNATIONAL SUPPORT STRUCTURES :



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