

Rare Diseases

Lions and rare diseases: a systematic approach

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Rare diseases are often very difficult to detect and diagnose. This is due to the fact that

- there are only few people in the world that suffer from such a disease,
- that these people are spread all over the globe,
- not all affected people live in big cities,
- and that it might take them a long time to see a medical expert,
- resulting in late diagnosis.

Facts and figures:

A rare disease is a condition that affects no more than 5 in every 10,000 people.

In Germany alone, there are now 4 million people suffering from a rare disease.

At the moment, around 8000 known conditions fall into this category.

Given the small number of sufferers, the pharmaceutical industry has no financial incentive to invest in research into these conditions with a view of developing a drug.

As there is no information policy or network in place, people find it hard to find out more about their disease.

Many rare illnesses are caused by genetic defects or rare infections. The group of conditions also includes auto-immune diseases and rare forms of cancer.

We should also not forget people who live with a condition that has never been properly diagnosed, which further adds to the suffering.

What can Lions do to help people affected by a rare disease?

At the Europa Forum in Istanbul, our friends from Italy first raised this issue.

Lions all over the world can get involved and help here:

- 1 representative per MD in Europe focusing on this topic
- Contacts to national health organisations
- The representatives from each country report back to the other Lions at each Europa Forum
- Presentations/activities in Lions clubs
- Annual report (MDR, EF, IC)

We can learn a lot from our colleagues in Italy, as they have already achieved a lot by helping individuals and by raising awareness (for instance through theatre plays that highlight the plight of people suffering from a rare disease).