

Helpline Seltene Krankheiten - improving patient care in rare diseases

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Abstract

In rare diseases, patients are rare, experts are rare and knowledge is fragmented. The unmet need is high, as is the burden on patients. Rare disease helplines have proven instrumental in referring patients, their relatives, and also other health care professionals to resources and experts. The Children's Hospital Zurich has been running a helpline for the German-speaking part of Switzerland since May 2016. The helpline is free of charge, available by email or phone, and serves both children and adults. In the first 22 months of service, 136 inquiries were received, mostly by email. Inquiries were mainly for adult patients, primarily made by relatives, followed by inquiries by the affected persons themselves. By far the most inquiries were for experts. Many inquiries were highly complex, requiring extensive research and contacts with our network of experts.

www.kispi.uzh.ch/helpline-selten

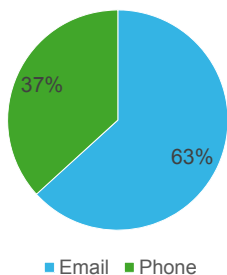
Background

Switzerland is a small country with 8 million inhabitants in four language regions. The number of patients affected by each of the many rare diseases is small and the different languages precipitate the problem. The hospitals of the University Medicine Zurich provide care for many rare disease patients. Rare disease helplines have been established in many countries to help address the challenges faced by patients. In Switzerland, a helpline serving the French-speaking region was already successfully set up in 2014.

Results of the first 22 months

Since 2016 the "Helpline Seltene Krankheiten" is serving the largest language region of Switzerland, the German-speaking part.

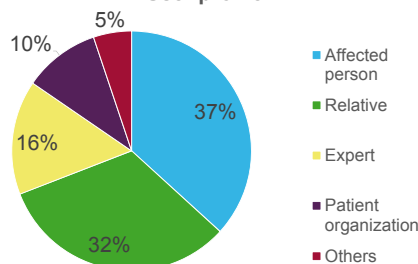
First 22 months: 136 inquiries



Inquiries were primarily received by email. Affected people represent the largest group of users, followed by relatives, experts, and patient organisations.

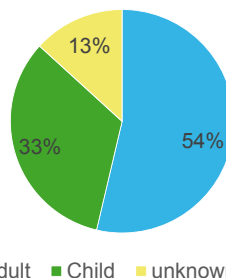
Acknowledgements: This work was funded by the Canton of Zurich, Switzerland through the project "Kompetenzzentrum für seltene Krankheiten – universitäre Medizin Zürich" via the HSM-2 program. We would especially like to thank our expert panels of affected patients and carers for their invaluable advice and helping us to better tailor our approach to their needs.

User profile



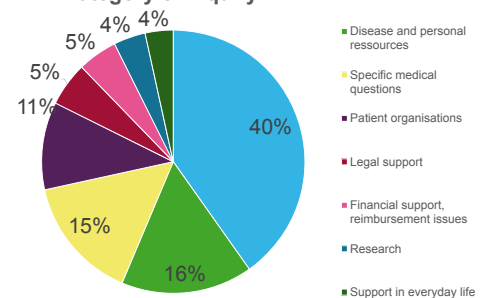
Help is being requested for more adult than pediatric patients, which may point towards a higher need in adult care.

Patient age



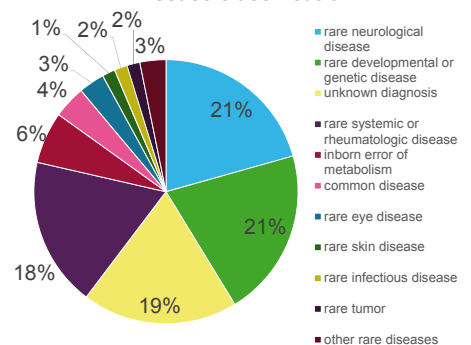
Clinical experts were most often sought. Due to the small size of Switzerland, experts may sometimes only be found abroad. Patients also look for contact with other patients and we have been able to connect patients within Switzerland and abroad. For rare diseases where there is an active network of experts and / or patient organizations, the helpline usually does not receive inquiries

Category of inquiry



Patients without a diagnosis were referred to the undiagnosed patient program at the University Hospital Zurich.

Disease classification



An effort will be made to make the helpline better known, but it remains unclear how patients who are unaware of the "rare disease label" and patients with lower internet and health literacy can be reached.