

Innovative approach in managing rare disease helplines - Rare Diseases Helpline: an between the Croatian Alliance for Rare Diseases and University of Zagreb School of Medicine¹

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The Croatian Alliance for Rare Diseases is a humanitarian organization rallying those diagnosed with rare diseases or disabilities. The Alliance provides professional assistance to patients and helps them claim their rights.

There is a need to provide fast and professional help to people living with rare diseases. Recognising this, the Alliance contacted Croatian Medical Students' International Committee (CroMSIC), and the „Rare Diseases Helpline“ collaboration was born in May 2014.

The University of Zagreb School of Medicine is the largest Croatian school of medicine. CroMSIC, having a local office in the School, found eight volunteers among the enrolled students to devote their time to the Alliance's cause.

The students, the above authors, are assigned to check the e-mail account by which patients' inquiries arrive. All students have clinical experience which, combined with their knowledge and access to medical databases and literature, enables them to extend professional medical advice regarding the inquiries. They help patients comprehend their disease, diagnostic tests, drug side effects and more, at the same time giving psychological support.

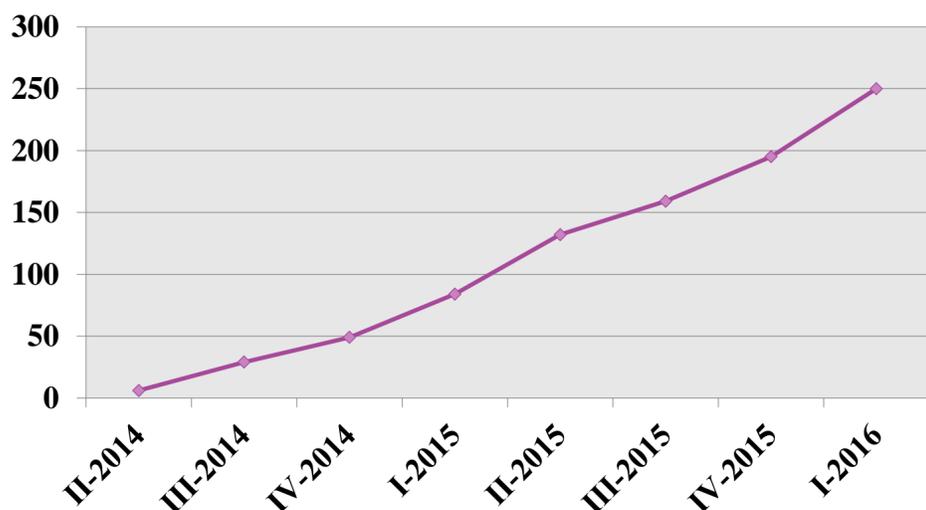


**Croatian Alliance
for Rare Diseases**



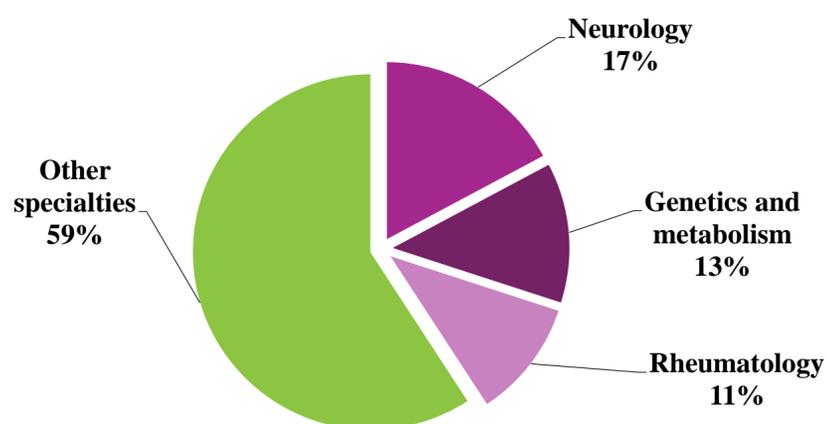
CroMSiC
Croatian Medical Students' International Committee

Total number of inquiries, N=250



From June 2014 to March 2016, more than 250 inquiries have been addressed. From the chart it can be seen that the number of inquiries constantly grows.

Distribution of inquiries by specialty, total N = 250



Pathologies of genetics, metabolism, rheumatology and neurology make up more than 40 % of the inquiries. Among other specialties, dermatology and haematology follow by 11% and 9%, respectively.

We hope to inspire similar projects, hoping that the access to free professional medical help and advice will be a standard practice.