



9<sup>th</sup> World Congress on

# Rare Diseases and Orphan Drugs

June 17-18, 2019 | Berlin, Germany

## Keynote Forum Day 1

Rare Diseases Congress 2019

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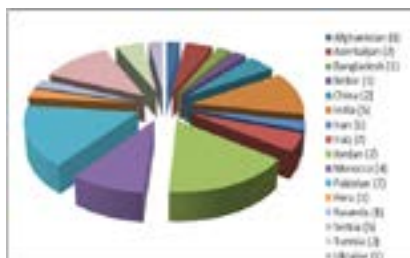


## Vesna Aleksovska

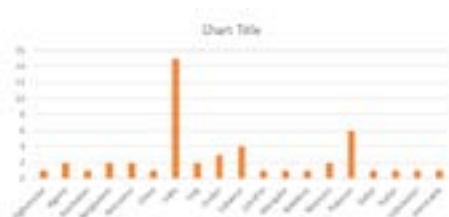
International Gaucher Alliance, Macedonia

### Humanitarian aid in the frames of International Gaucher Alliance

The vision of IGA is-A world where all Gaucher patients have access to the treatment and care they need and there is a possibility of a cure. IGA has the mission to be the global voice for Gaucher patients and their families; to empower its members to advocate on behalf of Gaucher patients to ensure that the Gaucher research agenda is focused on patients' unmet needs to take collective action to address challenges Gaucher patients worldwide face in accessing early diagnosis and optimal treatment and care. In the field of humanitarian aid IGA has achieved a lot with the following activities: Contact to affected patients and families; Working with the Pharma Companies e.g. Shire's Global Steering Group, Pfizer, Genzyme; Building infrastructure i.e. Jordan; Early diagnosis working with the industry; Cooperation with physicians and scientists; Influence on EWGGD and research.



We have helped these Patients in 2014 and 2015



We have helped these Patients in 2016 and 2017 (48)

### Biography

Vesna Aleksovska has founded the Association of citizens for rare diseases "LIFE WITH CHALLENGES"-Bitola in 2009. She is a Gaucher patient and patient advocate for rare disease patient in R. Macedonia. She is also a co-founder and former President of the National Alliance for Rare Diseases of R. Macedonia from 2014. She is now in the Board of NARDM and also in the Board of the Alliance of Patient Organizations of Macedonia. In 2013, she became a Member of the DITA (Drug Information, Transparency and Access) Task Force EURORDIS (European Organization for Rare Diseases) and a Vice Chair and Director in the Board of Directors of the International Gaucher Alliance since 2014. She is also a EUPATI (European Patients Academy on Therapeutic Innovation) Fellow, Trainer and EUPATI Ambassador for Macedonia.

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