Editorial

Title: European Migration Crises: The Role of National Hemoglobinopathy Registries in improving patient access to care

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The majority of the most common hemoglobinopathies, which include sickle cell disease (SCD) and thalassemia, are not indigenous to Europe but are now becoming prevalent. In this issue, Cela et al (1) report on the first Spanish National Registry of Hemoglobinopathy, which provides an opportunity to recognize and address this increasing prevalence. The authors report important epidemiological and public health outcome data from 715 eligible patients. Barely 15 years following the first report of a case of SCD in Spain, the average number of new cases has risen from 1.7 per year before 1996, to 42.2 cases per year in the 5-year period between 2006 and 2010, while those for thalassemia remain relatively unchanged (0.3 and 3.3, respectively). This reflects the pattern of migration to Spain mainly from African countries. The main European Union migrant population groups come from areas with a high prevalence of hemoglobinopathies (countries in the Middle East, North Africa and Sub-Saharan Africa). However, Italy and Spain receive mainly African immigrants due to their geographic proximity, while Greece and Central European countries receive more patients from the Middle East Region (Figure 1).

A survey of the European Union reported that areas of low incidence such as Sweden and Spain, have very low awareness of hemoglobinopathies and this leads to under-diagnosis and lack of access to care for ethnic minority populations (2). Only a few countries – Cyprus, UK, Belgium, Italy, France and Greece – have national or targeted education campaigns to raise awareness about hemoglobinopathies. However, with current trends in migration this situation may change, and historically low prevalence regions will now need to care for increased number of patients with major hemoglobinopathies. Therefore urgent action may be required within a short time to meet the challenges and address the opportunities.

Similar trends in the pattern of hemoglobinopathies were reported in Canada a generation ago, with a fall in the British population from 60% in 1871 to 45% in 1971, and an increase in French Canadians from 10 to 30%, leading to a rise in thalassemia prevalence (3). Furthermore a report from the UK (4) showed a decrease in utilization of prenatal diagnosis by migrants from Cyprus, and an increase among those from Pakistan and Sub-Saharan African countries. The current report of a comprehensive National Hemoglobinopathy Registry in Spain provides further evidence for the need to implement nationwide collection of data in hemoglobinopathies.

The benefits of establishing registries have been recognized in many countries. As stated by Hullihan et al (5) “a comprehensive understanding of the impact of hemoglobinopathies in the USA is important to public health practitioners, researchers, health insurers, and policy makers.” In the United Kingdom (UK), the earliest registries for SCD and thalassemia were developed independently (6, 7). Following the implementation of universal newborn and linked antenatal screening for hemoglobinopathies in 2004, it became apparent that a full comprehensive national hemoglobinopathy registry in the UK for both SCD and thalassemia

was imperative (8). In 2009, the National Hemoglobinopathy Registry was implemented and by 2013-14 the majority of patient in England had been registered

(http://www.nhr.nhs.uk/wp-content/uploads/2015/10/NHR_AnnualReport_2014.pdf). A national steering committee made of a multidisciplinary team is responsible for reviewing the content and governance structure of this registry. This effort is led by the UK Forum on hemoglobin disorders (http://www.haemoglobin.org.uk/) and two patient user groups: Sickle Cell Society (http://sicklecellsociety.org/) and UK thalassemia Society (http://www.ukts.org/), which raise awareness and resources to provide detailed patient information, treatment and newborn outcomes.

National hemoglobinopathy registries across Europe will enhance monitoring of changing demographics, service delivery and patient outcomes. In order to achieve comprehensive coverage, it is necessary to consider innovative ways to increase patient registration and accrual into the databases such as inclusion of:

i) Hospital medical records to synchronize with registry data and become a source to update patient management and outcomes;

ii) Population demographics to include details about ethnicity and heritage, which may be utilized to establish the target population for screening and intensive enlightenment through their community organizations and social network;

iii) Insurance data that could also enhance national registries.

Appropriate funding of registries is a challenge that can be surmounted only through effective advocacy and engagement of commissioning organizations. The fact that registries may cost only a fraction of patient care should be an incentive for those commissioning services and could enable the development of services for patients in affected communities.

The role of surveillance systems for hemoglobinopathies, such as registries, is significant for the allocation of resources and public engagement and the data may facilitate policy making decisions. By providing an overview of the demographic pattern of hemoglobinopathies, they are essential tools for monitoring patient outcomes. As stated by Cela et al and others, they also provide an important resource for research. It is reassuring to note the cost of running a registry is affordable (7), and offers a resource for economic planning for equitable care and service improvement. The development of national registries needs to be supported by rare anemia networks such as the pilot European Network on Rare and Congenital Anemias-ENERCA, or the recently established European Network- EuroBloodNet in order to foster lessons from countries with advanced programmes. Non-European countries, such as those in the Middle East and Sub-Saharan Africa, where the vast majority of patients live, may

benefit from such examples of good practice in order to utilize their limited resources appropriately (9,10). In the long term, we should adopt an approach capable of facilitating effective collaborations and sharing good practices between countries of high prevalence but low in resources and those with lower prevalence but well-developed pathways of care.

Conflicts of Interest: Both Dr Baba Inusa and Dr Raffaella Colombatti confirm that they have no conflicts to declare

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Figure 1. Migration to Europe; countries of origin and destination January to November, 2016. Permission to reproduce figure granted by the International Organization of Migration.