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THE SMASH program: an international network to improve care of patients with rare or severe hyperlipidaemia

A group of founders from around the world have launched the SMASH (System and Molecular Approaches of Severe Hyperlipidemia) program to facilitate access to accurate diagnosis and personalized treatments, including emerging therapies, for patients with rare or severe lipid disorders.

SMASH is an international non-for-profit philanthropic organization. The program aims to be a collaborative international network of researchers, clinicians, patient organizations and stakeholders involved in the management of patients with rare or severe lipid disorders to document the natural history of the diseases and ensure access to affordable therapies.

Patients with rare diseases have limited access to effective (new) treatments. This may be due to a lack of sufficient data on the natural history of the disease and the benefit from novel therapies in these patient groups. Payers often require data to reimburse treatments, but this is difficult as the numbers of patients with these diseases are small. Reimbursement issues are especially critical in emerging and developing countries.

Miriam Larouche, the coordinator of SMASH (Chicoutimi, QC, Canada) said: 'Besides reimbursement issues, hurdles to access to accurate diagnosis and treatments are huge; patients living in remote regions, far from the urban centers, patients living in emerging economies (in some countries, electricity is unstable, so they are not able to keep biodrugs), patients misdiagnosed living far from a lipid expert, etc.'

The SMASH program will benefit from the deployment of the EAS Lipid Clinic Network on four continents to increase sample sizes and aims to connect with scientific societies and patient associations to disseminate information and action plans.

'We are in an era of precision medicine where drugs are expensive and access to accurate diagnosis and treatment represents a real issue. In rare lipid disorders, we need to network and create initiatives to map and document the natural history of diseases to better understand biological pathways, target new therapeutic avenues and provide accurate medical care to patients. SMASH will not replace or duplicate what is existing. SMASH wants

to map, support and network existing initiatives on rare lipid disorders in addition to facilitate the development and networking of new ones. We intend to develop and maintain a philanthropic dimension in SMASH: under the principle of equity, people affected by rare lipid diseases should have access to accurate diagnosis and optimal treatment regardless of their living environment and social status,' added Miriam Larouche.

Larouche M, Catapano L, Arca M, et al. The SMASH program: an initiative for greater access to innovations for rare or severe hyperlipidemia

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