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IX INTERREGIONAL CONFERENCE. NEW CHALLENGES IN THE MANAGEMENT OF CONGENITAL AND ACQUIRED BLEEDING DISORDERS: FROM NEW THERAPIES TO THROMBOTIC COMPLICATIONS

The evolution of the therapeutic management of congenital and acquired haemorrhagic coagulopathies have reached levels that were unthinkable until a few years ago; especially as regards hemophilia: the forthcoming marketing of gene therapy and the new non-substitutive subcutaneous therapies and the latest concentrates, with a much longer half-life than the available products we have had in the last 20 years, has changed the way of "thinking" the treatment of these pathologies; especially as regards the haemostasis laboratory which, above all in the latest period, was characterized by the loss of its identity: this was due to the centralization of hospital laboratories and the lack of personnel with experience in the field of coagulation; now we are facing new realities where pharmacokinetics is carried out more and more rarely, also due to the diffusion of non-substitute therapies, whose laboratory evaluation, useful but no longer indispensable, is complex and not feasible except by a few laboratories. These innovations, however, have undeniably made it possible to improve the quality of life of our patients, maintaining therapeutic efficacy and above all, they have allowed us to aspire to objectives, first of all the prevention of joint complications, in a much more efficient way than to what has been done in the recent years. The fruit of all this is what we can see now: the increase in the average life span of the patient and access to all kinds of work, sports and social activities, which are absolutely no different from the general population. The increase in life expectancy, in particular, has forced haemophilia centers to take into consideration thrombotic and cardiovascular pathologies which, although this happens more rarely, also occur in adult and elderly patients with severe haemorrhagic coagulopathy. It therefore appears necessary to organize educational medical events which allow participants to update their knowledge by turning their attention not only to anti-haemorrhagic therapies but to a broader picture concerning the management of haemocoagulative emergencies at 360°, not only congenital but also the acquired ones that may require multidisciplinary skills until the problems have been resolved. So again, this year the Interregional Conference, now at its ninth edition, has as its target the improvement of a global treatment system which concerns not only pharmacological therapy itself, but involves, in addition to the haematologist, numerous professional figures, from orthopedics, to the infectious disease specialist, from the physiatrist to the psychologist, from the nurse to the biologist and the physiotherapist.

Traditionally, the second part of the conference was dedicated to associations, that fundamental part of voluntary work which includes families as a social entity most involved from a welfare and therefore



psychological point of view. First of all, the patient and family associations have the objective of affirming the rights of those who, being affected by a rare disease, are forced to deal daily with the problems linked to the disinformation of the institutions at various levels; they are also aware of the necessity to avoid the cuts in health care, to which the citizen has now been forced get used to, especially by the pandemic emergency, affecting not only the quality of medical assistance but also the availability of the treatments themselves. The purpose of the IX Interregional Conference of the Associations, held in Catania (Italy) from 3rd to 4th of December 2022, was therefore to inform and update all those health professionals who may have to deal with coagulopathic patients or with acquired bleeding emergencies during their professional activity on the methods of treatment and approach to various clinical, pharmacological, administrative and social problems. The meeting between the associations aimed to take stock of the current health situation, from the patient's point of view, to improve the management strategies of doctor-patient relationships, and between patients and institutions.

