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SHARING EXPERIENCE REGARDING HEMOPHILIA: THE ACTIVITIES OF A LOCAL HEMOPHILIC ASSOCIATION

Born from the need to establish sharing relationships between families with haemophilic children and with haemophilic adults, the Haemophilia Association of Reggio Calabria has always moved around the area trying to use all the possible resources it provides. Meetings were organized between families to share their experiences and their own experience with the disease. Meetings between families and expert mediators and psychologists to understand better how to explain the existence of the disease to their children and face the difficulties of everyday life. The children related to each other, sharing the experience of growing up, of facing a reality that is

not always the same as that of others. The various convivial moments, including with adults, have made it possible to establish a strong link between the past, present and future of haemophilia in everyone's life, in the innovation of treatments, in the new possibilities of approach. Not infrequently, in facing the diagnosis of a rare pathology for oneself or for one's children, the first feeling is that of loss and loneliness, as if what has happened to us is an event that cannot be shared with anyone else, which cannot be understood and above all unique because rarity makes you feel just like that, rare, unique in the most negative sense. The possibility of



sharing despite a thousand differences, listening to each other, seeing those around us overcome obstacles, being able to speak freely with the certainty of being understood, without having to explain, justify and have to make the best of inquiring and uncertain looks, is one of the added values of the our Association and of associations in general, which came to life from being



together. Precisely because of being together, in recent years, the Association has carried out various activities

in the area. Swimming instructors were trained and young and adult hemophilic patients were given the opportunity to attend swimming lessons in the pool together with all the other users, thus promoting integration as well as healthy movement. A similar activity was also started in the gym, always starting from staff training and developing guided courses for the different needs of children and adults with hemophilia. Due to the fact that the consequent pathologies associated with hemophilia affect the joints, physiotherapy screening programs have been launched which have made it possible to monitor the growth of children and the real conditions of adults, preparing the necessary interventions in collaboration and synergy between doctors and patients.



The relationship with the closest and even distant associations has given rise to congress moments where there has always been a space dedicated to patients. Therefore, within the same event, clinicians can exchange their considerations, studies, experiences, while patients can express doubts, perplexities to doctors and learn the state of the art in research and in the situation of new treatments. On behalf of the association, transversal issues are also addressed such as the history and narration of yesterday and today regarding hemophilia with the aim of keeping the attention on this disease and complications always alive, but also to promote correct knowledge to everyone and not just to professionals. In conclusion, the Reggio Calabria Hemophilia Association has always tried to reconcile the two key aspects of associations: sharing the problem to dispel the perception of loneliness and helplessness and the promotion of activities that improve the patient's quality of life and of his family and create a relationship of full trust with doctors, trying to pursue the goal of personalizing care.