

# EXPLORE BARRIERS AND FACILITATORS TO IMPROVE THE INVOLVEMENT OF PATIENTS WITH REAL-LIFE EXAMPLES

García-Pulido Rafael<sup>1</sup>

*<sup>1</sup>President of the Spanish Association of Spina Bifida (Spain).*

Firstly, we want to show our appreciation for having been kind enough to invite us to this X Symposium on a topic that, sometimes, may influence our day to day.

As a person with spinal bifida in its myelomeningocele stage, at the sacral-lumbar level, and as a representative of the Association of Spinal Bifida Malaga (A.S.B.M.) is a comfort knowing that there are people and entities willing to respond to our ulcers that may be chronic in many of us, with all that implies.

We can say that the main barriers that we have encountered in being able to work for the prevention and treatment, in our city, would be, among others:

The non-existence of a unit or a reference center for prevention and treatment.

The diversity of opinions (treatments) with the same problem (clinical variability)

Being persons with reduced mobility, causing the movement to "nowhere", better not to do it.

The lack of training for the professionals who must deal with us.

The lack of information that comes to us in this regard.

Last but not least, the lack of self-awareness of our population faces such a critical problem.

In terms of the facilitator, it is not more than our own experience with lesions that are repeated again and again in spite of the fact that we have all the possible prevention, I think that having our real testimony will be even closer to the possible theories of intervention to the reality.

We have different testimonies, my own among others of everything said in these lines.

Testimonies of different diagnoses, different solutions (some traumatic for the person)... before the same lesion.