

PROJECT STARE ASSIEME

... A TRUE STORY!

November 2013

Celebrating anniversaries is something you just cannot get away from, but I must say that celebrating the **10 years of STARE ASSIEME** has been a real joy for me.

More than once during this tenth anniversary, I have thought about the meaning of this custom and the project itself: what is it and what lies behind it?

Born quietly, it became a subject of research with the publication of the book "La Cura Associativa" [Associative Care] in 2010, project Stare Assieme [Being Together] has been described as a dispenser of care and opportunities, a way of learning associative resilience, and the possibility of seeing the wide-ranging research and sensitisation activities of AST ONLUS [the non-profit Tuberous Sclerosis Association] put into practice.

After a considerable amount of preparatory work collecting data and information, these days represent an educational and experimental workshop for the disabled and their families, and provide an opportunity to meet and exchange views and ideas with the other associations operating in different parts of Italy – an opportunity to bring out "invisible data" in order to make up for the lack of information and published findings that is common to all rare diseases.

We should not overlook the "halo" effect: the activities of AST in Stare Assieme are intended to communicate the way in which it sees the work of an association such as ours in its broadest sense, and this often reaches the institutions that have gradually become increasingly closer to the project itself.

Over the last few years, the principle underlying associative care has become increasingly concrete, which many see in terms of finding

a physical place, a roof and a piece of land on which to construct the future of their children, and others see as learning how to cope with themselves and their emotions.

Another thing that should not be overlooked is the effectiveness of social tourism: the local representatives of AST have created an itinerant project that reflects the geography of the country. During its ten years, ten different Regions have enthusiastically welcomed the arrival of the Italian group: Tuscany in 2003, Sicily in 2004, Campania in 2005, Abruzzo in 2006, Sardinia in 2007, Apulia in 2008, Liguria in 2009, Calabria in 2010, Marche in 2011, Basilicata in 2012, and Emilia Romagna in 2013.

Comforted by the sense of group feeling, offering an opportunity to get to know Italy in an associative manner gives greater substance to the unity accompanying the project participants, and the rich and varied landscapes of the country stimulate the ability to think and be creative. The splendour of the Italian cities of art remain indelibly fixed in the memory because they have been visited arm in arm with other members of AST who normally live hundreds of kilometres from each other.

As Manuela Magni, the coordinator of the representatives of the associations in Emilia Romagna, called it during the course of tenth edition, it is a centre of AST energy.

And now this poster-calendar, which is ready to be published at the end of 2013, not only provides a nostalgic photographic souvenir of the ten years we have spent together, but also brings with it an expression of our intent to continue telling our story in the international language of English.

There are therefore aspects of why we are together: are you together too?

Velia Maria Lapadula
PRESIDENTE NAZIONALE AST ONLUS



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SCLEROSI
TUBEROSA