Just 15 days after the European PanCare Annual Meeting (Genova, Italy), "The race of brave bikers" took place. This "race" is dedicated to young adults and adults who survived a cancer during childhood. An opportunity to meet and especially thinking on: what about building a European network? The “Aggueris” were present!

The program PanCare PanCareSurfUp promotes long-term effects studies monitoring patients treated for pediatric cancer. Doctors and scientists from all Europe try to bring together existing researches and promote initiatives within a single research framework (common protocol).

PanCare is a multidisciplinary pan European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long term care.

15 days after the Annual European Congress, in the north of Italy (Veneto) and for the second consecutive year, the cycling spring race the "Granfundo Fi’zi: K", hosted a festive event which gather all the Aggueris coming from 11 European countries. But most of all it was a special opportunity for us to get together and share collectively the challenges to go ahead with.

These exchanges allowed to evaluate practices in Europe and show a field of work for the Aggueris which seems far more important than we envisioned. Indeed, PanCare clearly called "survivors" (so called in English) to initiate an adult and young adults childhood cancer survivors network. The aim: bringing together on a European scale in a structured network adult national organization.
Why?

Just 10 years ago, after the remission period (and therefore medical care) was passed, patients walked away "in nature." The question of making a child knowledgeable of his/her personal medical history did not arise. But years passed and little patients now adults had no specific medical information about their cancer and its treatment as well as information and advice about the risks of long-term effects (and very long) term.

Unfortunately, this is still the case today, but this matter has been arisen NOW by professionals and parents' associations.

Forty participants from 11 countries

As a fledgling organization, several key elements are feeding our understanding of French and European context but also the extent of the need and actions. From this point of view the long term consultations developed since 2 years by the IGR are a pioneer project in France and Europe.

Pioneer also as we get access to the Public Organisations databases in order to “find” survivors.

The association Aguerris therefore falls within this innovative movement.

We discovered in Italy that the creation of specific groups of adults is not yet shared in European countries. In fact, when there are formal organizations, they are all NGOs for children and parents of sick children as they also exist in France (such as ISIS and federation UNAPECLE). In the best cases, these groups of internal working groups are made for long-term monitoring.'

Some spices for a European Network Recette

However, a consensus has been reached this weekend on the need to start developing working tools to create a network and promote the creation of such "autonomous" adult associations in connection with the existing children or parents associations.

Sponsors who provided us with funding for Italy are committed till 2016, so we have two years ahead of us and two annual meetings to review, progress and achieve this goal.

The three representatives from the Aggueris proposed the establishment of a small working group to administer an Internet tool that will share our goals and how to achieve them.

A first step to better influence policy decisions maker and target funding. Together. The Aguerris, doctors, scientists, parents, we will improve the monitoring and quality of life of adults who have been treated treated of a childhood cancer.