

 **1**ST **EUROPEAN**
DAYS OF
ALBINISM

Organized by
association française
Genespoir
des albinismes

October 27th & 28th 2012

Paris, FRANCE



Web



As you know, our association is not formally established.

Why we made this choice?

Certainly not because we are against associations, which we have already said we recognize the irreplaceable role and functions of, but simply because we set different goals to pursue.

In fact, to accomplish our modest projects we thought we would not need an expensive logistical and bureaucratic apparatus, which would halve our resources at the expense of the same.

We also made some simple assessments of what the network could offer in terms of immediacy of communication, exchange and dissemination of information and their impact on the media.

If we add the convenience of getting all this while sitting on the couch at home, interacting at our best convenient time, with someone who is hundreds of miles away also comfortably sitting at home, then we had no doubts on what and how to do it.

Consider also the fact that it is essential to talk to another person about topics of interest, if you want to and when you want to, because this generally coincides with the moment when each of us give our best in terms of ideas and efficiency.

Add also the fact that we people with albinism are so rare that we are far apart from each other on the national territory and in any case we would not have been able to gather so often as we do online.

This does not exclude the meetings that we organize to examine in depth the exchange that has already taken place "virtually", rather let's say that we organize meetings and conferences when a fervor and a number of matters to be discussed and explored have arisen from online discussions.

Meetings and conferences of which we publish images, videos and documents in order to increase acknowledgement and awareness of issues related to albinism.

When we founded the site, social networking was not yet widespread.

The main objective was in fact to let people know what albinism is, opening up to the world and not to create a protecting and comforting shell.

We did not and do not want to claim rights or defend others, this is not the task we set ourselves, but rather we want to spread correct information in order to break down the barriers that cultural ignorance have risen at the expense of integration.

In a world that moves fast and changes with the speed of the wind, especially in this area, we must keep up with innovation and follow the evolution of social platforms.

So we got fully involved in groups created on all the different social networks, where we actively participate in the discussions, we are proactive, we collect proposals and open new channels of communication, even if we find some impediment with language

barriers.

Our move towards social platforms does not diminish the importance and value of the web site which remains and will continue to be a container of a variety of information, accessible by anyone, at any time.

In our opinion, one does not exclude the other, on the contrary, they are integrated and mutually reinforcing.

The goal is that our space is everyone's, an open space that wants to be a sounding board for all the initiatives in favor of people with albinism and to share what has been done to overcome the problems that this condition implies.

It is also important to share important initiatives like the one we take part to today, and we ask you to collect the acts of this conference and make them public through our website and others, so that as many people as possible can know and appreciate our work and that of the professionals present here during these days.

Certainly we do not claim to have the rights, but we want to contribute to the mediatic success of the first European conference on albinism and its future developments.

Because making known that we did meet up, will make many other associations and communities want to do the same, they could take advantage of this experience to meet one other and who knows maybe during a next meeting join us.

What we see in our future?

- The expansion of the integration with social networks, to and from the site;
- The creation of a section called "diary", to collect information about events of different nature, related to albinism, and its issues;
- The development of the portal so that we can put in communication people with albinism with qualified, accredited professionals, whose CV will also be published. We would like to create a proper telemedicine portal.

This would allow people with albinism and their families to avail of targeted expert advice, direct and confidential, while the scientific community would have the opportunity to examine a larger number of patients than in the territory in which it operates and to exchange important information.

All this of course completely free of charge.

Thank you for your attention

The staff of www.albinismo.eu
(translated by Laura Fucci)

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