



2nd Conference and National Meeting

ALBINISM: A LIVEABLE DIVERITY

Knowing it helps to understand,
sharing helps to grow up.

Rome – 9th July 2011

Conference Center
Hotel Divino Amore Casa del Pellegrino
Via del Santuario, 4

**Presentation of the conference,
work done by the website and future plans.**

Speaker: Giancarlo Loddo



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Good morning everyone.

My task is to present the conference, to update you on the work that has been done by us in recent years and show and share with you some ideas to be implemented in the near future.

As I speak, you will see on the screen a series of images which illustrate the website, past events and the most significant sentences written by you in the discussion forums or as a signature in your profile. Those who have difficulty seeing the screen can read the sentences in the booklet containing the abstracts of the reports.

First of all, for those who don't know, my name is Giancarlo Loddo and I refer here as the founder of the website www.albinismo.eu.

I do this qualification because in Italy there is another website that deals with albinism and with whom at present there is no form of cooperation, also an association called Albinit is represented here today and a manager will report on the work of the association during the roundtable discussion this afternoon.

I refer these things because we often receive correspondence that somehow associates us with other entities, asking for explanations or clarifications which we can not provide.

Personally, I believe (speaking on behalf of all the staff of [albinismo.eu](http://www.albinismo.eu)) that this is not a problem but an advantage for all the Italian albinos, because they have the opportunity to receive informations from more sources and use different services provided by multiple entities, so that they can make a comparison in total autonomy and understand those who best meets with their needs.

This pluralism can only be an asset and can not and should not be a cause for division in the accomplishment of common projects . On our side has always been and will be guaranteed a willingness for a healthy comparison, for dialogue and cooperation with everybody and for the good of us all.

[Albinismo.eu](http://www.albinismo.eu) is a web portal founded by myself and managed in total partnership with other collaborators who over time have joined us and who like myself operate purely by volunteering.

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At this moment we have about 200 members, but many more people read and observe our work quietly, many write to us and ask to maintain confidentiality and anonymity. Someone breaks the silence occasionally entering the fray and even deciding to actively collaborate with our project. Others continue to wait for the spring that will make them proudly come out from anonymity and decide to have their say and helping the whole community. We peacefully wait for them, we are aware of being their point of reference and they are a resource for us too, this is already enough for us and fills us with pride, it means that for now we are sowing good.

From some years now we are committed primarily to provide an information and support service both psychological and social to albino people and their families. We are eager to raise public awareness about the problems inherent albinism, organizing events and conferences whose contents are published in full.

To achieve our targets we work with serious and qualified professionals, facilities and medical associations. An ample space is dedicated to the direct exchange of information, ideas and opinions among members through blogs and discussion forums, to make sure that what we like to call "our community" is increasingly broad and open to new ideas and initiatives.

We focus on the accessibility of contents and the quality of the information given, without any distracting and annoying banner ads.

We do not ask and we do not handle money in any way and we intend to do so in the future not to damage with any economic interest the wonderful relationship that we created with our members, so that we can work in total autonomy, transparency, and complicity.

We do not intend to institutionalize us because we believe that to achieving our modest goals is enough just a little spare time, common sense and a spirit of collaboration, listening, mediation and a lot of good will.

Our goals are within our reach, we organize ourselves to achieve them, intervening in person to address the economic side without let it go to our heads

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and eventually think about what to do next capitalizing ourselves and growing each time.

When we have to work with someone, we evaluate the proposals carefully: if the ends are not clear or if we believe that the cost-benefit ratio is not appropriate, we prefer to let go.

We are not too ambitious, the resources available are limited and we prefer to be devoted to small things unlike some others more ambitious than us that not realize that what they leave out is the most useful thing and bring an immediate benefit to those in need.

This is albinismo.eu and should remain so.

From its foundation to today, as well as to organize the 1st National Conference and Meeting on Albinism titled "Pale by nature", which was held in Sardinia in May 2009 and whose acts and movies are fully published and usable by all, the website has maintained the commitments made during the first event. We then worked to promote and inform on two projects that we feel are important and which are managed by health care facilities of national importance. I refer to the diagnostic multidisciplinary Hospital Niguarda Ca 'Granda in Milan of which later we will have a report by Dr. Patrosso and Dr. Mauri, and the project on nystagmus research made by the Centre for the National Prevention of Blindness and Visual Rehabilitation of the Visually Impaired, with news firm Dr. Fortini and Dr. Piscopo.

We also made an important work of census, which is still continuing, and we try to keep it constantly updated, in relation to the centres for diagnosis and treatment of visual impairment and on the national territory.

We also surveyed existing worldwide associations that deal with albinism, blogs and private websites, including famous albino people or other people that have something in common with the topic.

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Given the extent of social networks, i have created a personal profile on Facebook and a page dedicated to the website and I made friends with about a thousand people around the world.

Even in Italy the phenomenon is catching on and facebook is becoming, even for albinos, the source of information and medium of exchange, and in the wake of the impact that the first national conference has had on media we founded several groups of discussion. Here are some of them: Albinism Italy - founded by Agnese Marchesini, Albinos in Italy - founded by Simona Cimino and administered with Federica Fassi, ALBINOLANDIA - founded by Amedeo Enrico Manganese, Pale by nature - founded by Francesco Dentici.

We needed this also to understand that it was time to open ourselves to the world, hence the will to translate the website into English. For this we thank the dear Alessandra Cabiddu for her translation work and the always present Gigi Mascia for allowing us to technically open this important window on the rest of the planet, which consents us to communicate and share important informations with a growing number of people, then turn these informations to the whole community.

What will we do in the future? After this meeting we will be making a long and important work on the publication of all acts and videos.

We'll need to update the section on press, TV and radio and work as always for the good prospects and suggestions which will certainly come out of this important event transforming then in concrete facts.

We will be vigilant and we hope that you will to.

We also have in mind to realize a series of videos with the researchers that will be available to spread on the web in order to raise public awareness on the importance of scientific research.

They'll be short length videos and easy to understand, the researchers will have the task to make the people understand what their job is, how much the scientific

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research costs, by whom and how it is financed and what the ordinary citizen can do to fund the research and how to possibly orient choices and monitor their implementation.

Clearly our projects are not just these ones, we'll notify you as soon as we'll realized them (a little 'for good luck but also not to appear presumptuous).

During these early years of the website, from both the correspondence we receive and what is been written on the discussion forums, we have noticed that especially the parents complain that there is no tool (texts, research, experiences, etc. .) enabling them to better interpret the discomfort, visual or otherwise, of their children so that they can try to improve this condition. There are also reported difficulties to obtain textbooks with large print before the beginning of the school and there is a total or partial lack of competence on the subject from both the school staff (managers, teachers and educators) and the medical staff (paediatricians, child psychiatrists, psychologists, ophthalmologists, orthoptists, dermatologists and family physicians).

Another important issue that is constantly highlighted is the discomfort experienced by children who have been confronted with the others during their schooling, particularly in elementary school. And this is the first experience that marks the idea of a different conditions. In particular we see, from what is written on the forums, that children do not tease them for the visual problems (which is the real discomfort) but simply for their physical appearance.

For children the difference seems to be what they see. And this difference would cause the first difficulty for those who live our condition.

It is emphasized that in all the stories of adults who have experienced primary school the discomfort appears to be primarily on a physical level, highlighted by the children to school. All seems to talk about it and tell with great nostalgia that they wanted to do something to prevent these episodes, almost to underline that they needed help and were not helped.

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This was a due premise because on the basis of what people say and asks us we decided to organize this second meeting, to try to give answers to these questions. Of course we do not have the ambition to provide an answer to all questions today, but we will start to work and create the foundations in order to reply them.

The 2nd conference on albinism stems from the belief that the limits placed by this genetic condition can be managed and somehow overcome, thanks to the awareness, the sharing and the competence.

Awareness alone is not enough because often we are not able to handle everything that we are aware of, so is important to acquire skills through a healthy and constructive sharing.

To give practical meaning to what we intend to do today, I want to quote Prof. Canevaro (we have also listed it in the brochure):

"Competence is like love: the more you share the more it grows ... if we exchange ideas. .. they will come up with other ideas ... but this needs a prerequisite. We must be able to listen ourselves. We must not be jealous of our ideas and we must know that others can get good ideas".

We have in our heart this desire and this "ambition". We want to provide an open space to medical professionals, teachers, educators, associations, parents and children to enrich and grow in humanity. This is the aim of the conference and we hope to hit it.

Now let me make a twist of congress rituals where usually the acknowledgements are made at the end when the speaker is tired and forgets to thank someone.

I wanted to tell you that the whole organization of the conference, the idea of starting to do it, think about how to organize it, who to invite and everything that concerns this important event is the result of an important and difficult work

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carried out by myself as well as two wonderful people that I now consider my sisters, these are Laura Bonanni and Isabella Macchiarulo.

We've been working on this project from almost eight months, in total harmony and freedom to share virtually everything. I hope to continue this wonderful experience and that we can achieve together in the future, perhaps with the help of others who want to join the group, other important goals.

I want to emphasize that they also did an economic sharing, because as you can imagine an event like this has costs and even these were equally divided between us. Thanks Laura and Isabella.

I would like to thank Carlo Tarallo, this time for his expertise on the subject: he has taken on the burden of care about the logistics and the management of booking the hotel stays for those who come from outside Rome.

He really saved us with an impending difficult to manage, we also need to thank him because he offered completely free of charge transfers to and from the airport of Fiumicino and Termini train station and tomorrow he will take us at St Peter Square for the Angelus and the Holy Father's blessing. Thanks again Carlo.

I thank the sponsors of the conference who not only believed in us and in the importance of this event but also want to collaborate in the diffusion of information material and have the willingness to continue to work together in the future to carry out joint projects.

I thank the Attorney Giuseppe Terranova, Vice President of the Italian National Union of Blinds and Visually Impaired for represent this great and historic association and Dr. Michele Corcio, Vice President of the Italian Section of the International Agency for Prevention of Blindness.

I also want thank the lawyer Giuseppe Castronovo, President of the Italian Section of the International Agency for Prevention of Blindness for his cooperation and for the presence of speakers that refer to the National Centre of Services and Research for the Prevention of Blindness and Visual Rehabilitation at the Hospital A. Gemelli in Rome, and the National President of the Italian

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Union of the Blind and Visually Impaired, Professor Tommaso Daniele, with whom I established contact directly and that, unfortunately, were unable to be here today.

I thank all the speakers for the work done and for that that they will present during the conference, they did it completely free of charge, paying for the costs of travel and stay in Rome. Thanks to you all.

Thanks to Dr. Maria Giovanna Faiella, coordinator of the Health pages of the Corriere della Sera newspaper, that this afternoon will be the moderator of the round table, she will take care for this important newspaper a comprehensive report on the conference.

I thank the Special Commissioner of the Blind Institute in Milan, Knight of the Grand Cross Rodolfo Masto for his availability and willingness to collaborate with us in the future and Prof. Giancarlo Abba, Scientific Director of the Blind Institute, during the course of the round table this afternoon we will illustrate the important activities that this institution, on the cutting edge in Italy and Europe, continues to offer in favour of blind and visually impaired. Thanks Prof. Abba.

I thank the hotel that welcomed us and generously granted us the use of the hall. I thank all the members of our community and supporters who wanted to be with us today but couldn't make it. Thanks to you all.

Finally and most importantly thanks to all the people who came, the albino brothers and sisters, their families, professionals, managers, teachers, and those who simply are interested in the topic or are here because dear friends, you all must know that you are our reward.

Thank you, good job and good listening at all.