1ST EUROPEAN DAYS OF ALBINISM

Organized by
association française
Genespoir
des albinismes

October 27th & 28th 2012
Paris, FRANCE

Presentation of the portal

Albinismo.eu

Hello,

This document aims to present the portal www.albinismo.eu, illustrate the work that has been done by us over the years, and share some ideas to be realized in the near future.

The site was founded by Giancarlo Loddo in 2007 and along side him it is currently run bsmall but very close staff that operates purely on a volunteer basis.

Dr. Laura Bonanni was the first to appreciate the ideas and objectives; among other things, we share with her the importance of decisively work over the social and psychological aspects of albinism and we thank her for her initiative and precious collaboration, for she offers others her experience and professionalism for free.

In order to be of help in this regard, we have opened a discussion forum open to all members who want to debate this specific aspect or ask questions to Laura who, compatibly with her job, is committed to give answers and feed the discussion, in the shortest time possible.

It is also possible to establish a direct and reserved contact via e-mail for specific advice.

Isabella Macchiarulo on the other hand, takes care of the technical and closely related to accessibility web, with extreme competence, patient and punctual collaboration makes our ideas a reality.

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Isabella Macchiarulo the other hand, takes care of the technical side of things and that closely related to web accessibility, with extreme competence, and patient and punctual collaboration she turns our ideas into reality.

She also works with precision in the management of all organizational aspects, both for conferences and events and also for other initiatives; always careful in managing relationships and timely with her responses.

Fabio Franti has always taken care of recording videos from the conferences that we post on the site; he also participated in the drafting of the text that was published in July 2012, alongside his wife Silvana Princi, Vincenzo Giarratana, Andreza Cavalli and others who wisdh to remain anonymous.

Two serious professionals Dr. Loredana Bite (correction: Boccone) and Dr. Maria Cristina Patrosso have respectively edited the section on scientific information and in-depth examinations of the syndromes associated with albinism.

At the moment we have a total of about 300 members scattered all over the country, but many more people read and observe our work discreetly, just think that in the month of September we had 2200 unique visits. Others write to us asking to remain anonymous, occasionally someone breaks the silence by joining the fray and decide to actively collaborate in our project. Then there are those people who are waiting for that inner push that will allows them to proudly come out of anonymity, deciding to have their say, in turn helping the whole community. We calmly wait for them, aware of being point of reference for them and them being a future resource for us.

For some years we have been committed primarily to provide an information and support, both psychological and social, to people with albinism and their families.

We take steps to raise public awareness on issues related to albinism, organizing conferences and events the proceedings of which are published in full.

To achieve our objectives we work with serious and qualified professionals, facilities and medical and health associations. Considerable space is devoted to the direct exchange of information, ideas and opinions among members through the blog and discussion forum, to ensure that what we like to call "our community" keeps growing and exposing itself to new ideas and initiatives.

We take particular care in content accessibility and quality of the information provided, without any distracting elements and annoying ad banners.

We do not ask for or manage money in any way and do not intend to do so in the future, for not to ruin with possible economic interests and power, the beautiful relationship created amongst us which allows us to work in complete autonomy, transparency, complicity and maximum share capability,

We do not intend to become institutionalized because we are convinced that to achieve our modest goals, all that's required is just a little free time, common sense and spirit of collaboration, listening, mediation and a lot of good will.

We set ourselves goals within our reach, we get organized to achieve them, personally dealing with the economic aspect, we take them out and without getting too big headed we think of what to do next, capitalizing and growing each time.

When we work with someone we carefully evaluate the proposals: if the goals are not clear or if we believe that the cost-benefit ratio is not appropriate, we prefer to leave it.

Resources are scarce and we prefer to aim them at the small things that the more ambitious than us overlook, not realizing that they are the most useful and bring immediate benefit to those in need.

Since the establishment, we have organized two conferences and a third event of national character.

We have worked to promote and inform on two projects that we feel are important and which are managed by health centres of national importance. The multidisciplinary diagnostic course set by the Niguarda Ca 'Granda hospital in Milan and the research project on nystagmus of the National Centre for the Prevention of Blindness and Visual Rehabilitation of the Visually Impaired.

We carry out a major survey in relation to centres for diagnosis and treatment and for Education and

Functional Rehabilitation of the patient with low vision, throughout the country.

We also surveyed existing associations in the world that deal with albinism, blogs and private sites, including those of famous people with albinism or that somehow relate to the subject.

Given the extent of social networks we have created a Facebook page dedicated to the site and have made friends with over a thousand people around the world.

Even in Italy the phenomenon is catching on and Facebook becoming for people with albinism source of information and a medium of exchange, in fact also in the wake of the impact that the first and second national convention had on the media, different discussion groups were created, which we are part of.

We mention them below, hoping not to forget anyone: Albinism Italy - founded by Agnese Marchesini, Albini in Italy - founded by Simona Cimino and administered with Federica Fassi, ALBINOLANDIA - founded by Amedeo Enrico Manganese, Fair by nature (correction: Chiari per natura) - founded by Francesco Dentici.

This helped us understand that it was time for us to open up to the world: hence the desire to translate the site into English. Work for which we thank Alessandra Cabiddu and the ever-present Gianluigi Mascia, for allowing us to technically open this important window on the rest of the planet. Now we can communicate and share relevant information with a growing number of people, and then turn them over to the whole community.

Throughout the years, both from correspondence we receive and what is written on the forum, we have noticed that parents especially complain that there is no tool (text, research, experiences, etc..) that allows them to better interpret the discomfort, visual and not, of their children so that they can try to improve their condition.

There are then reported difficulties in timely obtaining textbooks in large print and in the total or partial lack of competence in the subject both from school personnel(head masters, teachers and educators) and medical staff (paediatricians, child psychiatrists, psychologists, optometrists, orthoptists, dermatologists and family physicians).

Another important theme that is constantly emphasized is the discomfort experienced by who as a child has been confronted with others during their education, particularly in primary school.

This is the experience that first scars people and give the idea of a different condition. In particular we observe from what is written on the forums, that children do not make fun of the visual discomfort (which is the real bother) but simply of appearances.

It would appear that to children is what they see that makes a difference. This difference causes the first difficulties for those who live with our condition, because they become conscious of being different, and not nice or ugly.

In all the stories of adults who have gone through the experience of primary school, what mainly surfaces is the aesthetic discomfort, highlighted by the children in school. Everyone seems to talk about it with a lot of nostalgia, as if to emphasize that they had wanted to do something to prevent these episodes, as if to emphasize that they needed help and didn't receive it.

This important premise was necessary because on the basis of what people ask themselves and ask us, we decided to organize the conferences and write the book, just to try to give some answers to these questions.

The idea behind the 1st National Albinism Conference called "Fair by nature", held in Villanovafranca (a small town in Sardinia) in May 2009, came from two requirements: first to introduce to the public this genetics reality with all its peculiarities, through a dialogue among specialized professionals (from the medical to the more technical). Secondly to provide an opportunity for exchange about problems and needs that people with albinism and their families face in everyday life, giving all participants (professionals and not) the opportunity to enrich and expand their cognitive-experiential horizons.

It was also an opportunity for raising awareness that in recent years we are doing concerning the reality of albinism in Africa which was made public in Italy by

journalist Matteo Fraschini Koffi, who at the first National Conference, sent a few lines from Kenya on what is his experience with respect to this problem.
Matteo told with clarity, sincerity, professional competence and passion, of a chilling reality, without omitting very "harsh" details, but also giving voice to the hope and possibility for change that are already coming through, like the signs in "early spring".
We liked and seemed particularly significant, to quote a sentence from his message:

"... What is happening in parts of Africa regarding albinism shocked me.
So it is important to clarify: a human being born with albinism is not a ghost, he does not disappear with the wind, does not dissolve in water, does not dissolve in the rain, does not get any colour in the sun, does not die fading, does not cure AIDS, has no magical powers, does not fly, is not a child of the devil, is not necessarily rich and his physical condition is not contagious ...
I still remember the story of Africans with albinism as the most challenging and interesting part of my young career as a journalist.
The items and articles can be found on my website: www.matteo-fraschinikoffi.com."

In the wake of this very interesting report, during the Second National Conference held in Rome in July

2011, we decided to tackle the topic again collecting the testimonies of those involved.

We then extended an invitation to the conference to the representatives of the associations of the African continent that we had contacts for.

Mr. Aboubakary Sakho (National President of the Albinism association in Senegal - ANPRAS) accepted our invitation and we gladly hosted him in Rome.

Sakho illustrated the problems faced by people with albinism in the country, the objectives that the association sets and how we from Italy and other countries can help them.

During the conference sunscreen, sunglasses and hats where handed out which Sakho brought to Senegal and distributed to children with albinism in need.

The collection was carried out on the initiative of Mr. Souleymane Seck, who works in Italy, in collaboration with the Caritas volunteers from the Parish of Longiano (FC).

The 2nd National Conference entitled "Albinism: a liveable diversity. Knowing helps to understand. Sharing helps to grow" came from the belief that the limits imposed by this genetic condition can be managed and somehow "overcome", thanks to awareness, sharing and competence.

Awareness alone is not enough, because often we are not able to handle everything we are aware of. Hence the importance of acquiring skills, through healthy and constructive sharing.

To give what we wanted to do a sense of dimention, and we hope to have at least partially succeeded in that, we would like to quote a sentence from Professor Canevaro that we also report in the conference brochure:

"Competence is like love: the more you share, the more it grows ... If we exchange ideas ... they will generate other ideas ... though this needs a premise. We have to know how to listen to one another. We must not be jealous of our ideas and we need to know that others can have some good ideas too."

The idea of organizing a Third National Event entitled "Albinism Yesterday and Today" was born from the need for a serious exchange of views, direct and open among professionals, people with albinism and their families, in order to understand what are the practical solutions that everyone involved can apply in everyday life, so that this "diversity" called albinism is less and less considered as such.

Truth be told this need was manifested primarily by those who participated in the first two conferences and were particularly enthusiastic about the organization of the part dedicated to the exchanged of ideas.

So we decided to start from where we left off and devote most of the available time to confrontation, without preconceived filters.

During the latest event there was the presentation of the book which title matches that of the first two conferences "FAIR BY NATURE - Albinism: a liveable diversity. Knowing helps understanding. Sharing helps growing". Book strongly desired by the staff, who also fully funded its publication. Numerous professionals collaborated to the scientific part.

The text is designed to scientifically popularize what albinism actually is, what extent research has reached, what are the real chances of living a rich and fulfilled life, beyond the objective limits imposed by reducing visual acuity and the partial or total lack of melanin.

A book to explain in clear terms, with serenity and joy, that you can live and grow with albinism.

Our limitations just like our qualities, define us, make us unique and unique and this is the message we want to pass on: to parents, first of all, often disconcerted and frightened for the future of their children; to adolescents living in the "storm" of change, dealing with the strong desire to distance themselves from their parents and define themselves as people with their own identity; to teachers, to stimulate without prejudice and inhibitions, the emotional, cognitive, relational and expressive potential of these "different bunch".

Often the lack of correct information, as well as prejudice and rumours, generate confusion and build up limits.

That's why knowing is understanding.

Understanding is instrumental in stimulating the development of a healthy and adult growth. An understanding that also facilitates an adequate and mature sharing, breaking down taboos and shame.

During the life of a person with albinism, what is actually limiting is undoubtedly the severe visual impairment.

A book about albinism, strongly designed and wanted by people with albinism, could not overlook the question of legibility. Hence a book in large print.

Since this is a tool and a guide to support parents of and people with albinism, with no aesthetic influence, we chose not to distract the reader with images of albinism which might not have been suitable to the context or might have created false expectations not met with the actual contents of the text, resulting fragmented and giving a distorted picture of the daily life of a person with albinism.

After this important conference we are going to prepare our fourth event to be held probably in Sicily at the end of April 2013. Vincenzo Giarratana put forward this proposal, he has become a permanent member of staff and will take care of many aspects of the whole organizational phase of the event. This region was also chosen because there resides a large community of us, members of the the site also.

We would like to take this opportunity to invite all the representatives of the associations present here and their associates to attend the event. Not only that, but if you think it necessary to put forward your suggestions, please do not hesitate, so that this is could be an opportunity to bring together the largest possible number of people with albinism from Europe and the world.

With Vincenzo's help we are looking at the possibility of families of teenagers with albinism from Sicily hosting the largest possible number of teenagers with albinism from all over Europe. We then ask you to promote this idea and put us in touch with families that might be interested, bearing in mind that guests must necessarily be at least 16.

Seeing as we'd be dealing with minors we will of course try to make the most appropriate combinations, with our firm intention to involve the whole family in order to allow a large participation of children. We are considering the possibility, via some sponsors, to minimize the cost for the participants.

We will keep you updated on developments regarding the initiative.

Last of all, while realizing that at this conference we are a bit of an “anomaly”, we want to express our gratitude to the organizers for allowing us to introduce our project, which does not want to be an alternative to that of the organizations, of which we recognize the role and functions, but certainly complementary.

Indeed, we would like to be the “resonating chamber” for all those who in any way address the topic of albinism and deali with the problems experienced by people with albinism.

We believe in the pluralism of information, ideas and methods to achieve a number of goals; we think that this can only be an asset and can not and should not be cause of division, when we're all actually striding for the same targets.

For our part we will always guarantee good will for a healthy debate, dialogue and cooperation within all and for the good of us all.

In our hearts we have this desire and "ambition". We want to provide an open space for medical professionals and nt, for teachers, educators, associations, parents and children to enrich and grow in humanity.

Thank you for your attention

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

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