

PROSPECTS AND GOALS

Dear friends,

I am deeply moved to be here among you, on one hand because I am coming from a neighbouring country, and on the other mainly because personal reasons connect me with your country. My mother was born in Varna and my grand mother, and all my relatives as well, lived in Burgas and Sofia. All this makes me feel that I have a peculiar bond with Bulgaria.

I would like to congratulate you for the initiative you had to organise this conference for rare diseases and orphan drugs in one of the Balkan countries of Europe.

As representative of Greece, I would like to brief you about our efforts in establishing the Greek Alliance of Rare Diseases, which was started by a group of representatives of individual patients associations as well as of distinguished scientists in July 2003.

I got involved in this story, because my own daughter is suffering from Tuberous Sclerosis, a rare disease, a fact, which led us to organise the Tuberous Sclerosis Association

of Greece (TSA) in 1992. This association is a member of the European and International Association of Tuberous Sclerosis as well as a member of EURORDIS (European Organisation for Rare Diseases)..

When in June 2002 I was honoured, as President of the Tuberous association of Greece, to represent my country in the Board of Directors of Eurordis, the goal was to create in Greece as in the other countries in Europe, a strong agency that will bring out the problems of people with rare diseases and of their families and also it will promote and support their requests.

Moreover, it will inform the public opinion and the scientific world on the rare diseases, on the possibility of preventing them, on the diagnostic method, and on dealing with them.

It is therefore necessary to register the diseases and the patients in Greece, in order to establish a Data Base for the reliable updating of the scientists and the researchers on rare diseases.

The promotion of research that will lead to new drugs, therapeutic methods, and even the hope for cure of the rare diseases, is one more major goal to reach.

The access to reliable information will contribute to the improvement of the quality and the span of life of the patient, to better and more effective diagnosis, treatment as well as psychosocial support of patients and their families.

With this in mind, the Greek Alliance of Rare Diseases (GARD) has carried out with great success in Athens, a two-day conference in November 2004 on “Rare Diseases – Orphan Drugs”. Distinguished scientists, representatives of patients’ associations and of the public sector attended the conference.

As a result of the success of the conference and the very many phone calls from all over Greece, requesting more information on Rare Diseases, our Alliance decided and realized on May 2005 another event in the most central location in Athens (Constitution Square) displaying in special stands the work of Greek Alliance under the auspices of the Ministry of Public Health and Social Affairs.

During this event, information material, related to the activities of Greek Alliance of Rare Diseases as well as of the Patients’ Associations, was distributed. Scientists, who joined

the event, answered and clarified questions asked by the public.

Thanks to my long experience in the Tuberous Sclerosis Association of Greece and in facing the problems in the most direct way, that is to say within my family, I believe that, apart differences existing among diseases, the general problems which we have to face are common, such as:

- Lack of adequate and reliable information and training of physicians, a fact that often puts them in an awkward position and discomfort in dealing with the patient, who is confronted with the diagnosis of an incurable disease and is naturally intimidated and full of unanswered questions.
- The lack of needed psychological support – in and out of the hospital. A psychologist or a social worker is not always available to assist the patient to accept his situation and to inform him about his rights related to state social contributions.
- The patients have difficulties in acquiring the necessary drugs. Our common efforts and the presence of the state will help in aligning the regulations concerning the

drug legislation with that of the rest of the European countries, so that the patients have access to new and /or orphan drugs at the same prices.

- Another problem is the absence of coordinated efforts to increase the awareness and to inform the society on health matters. In combination with lack of education, this leads to the perpetuation and strengthening of attitudes and prejudices of the society towards the patient and his family.

I could go on and on mentioning the problems common to patients and relatives. Yet, I believe that what I have mentioned so far is enough to increase the need of cooperation among the patients' associations or other scientific society, aiming on one hand at the coordination and promotion of matters related to rare diseases, and on the other hand at the exchange of good practices with other countries.

I would like at this point to remind you, that officially the percentage of people with Rare Diseases in Europe is approximately 10%, and therefore in Greece we refer to about one million patients, who only if they are united can

assert and proceed to the solution of their claims, even by pressing the public services on the matter.

We believe that the cooperation between our two countries, and with the associations of other European countries, is imperative for the achievement of our common goals and for promoting the human approach among our patients.

One of the very important roles of the Greek Alliance of Rare Diseases (GARD) is that it can convey to the Eurordis the problems of individual Patients' Association. Eurordis in turn submits the petitions of the member countries to the European Parliament.

In this way, our voice acquires more power and it can influence decisions of our interest. We must bear in mind that the European Union embraces the patient with great respect.

We can reinforce the position of our patients and their families by adopting the good practices of the north-European countries, adding to it the sentiment and special temperament, which characterizes us, the Balkans. To this aim, we call upon all the patients' associations in Bulgaria and of the other countries, to contact the Greek associations and scientists to unite our efforts so that all together, with our

problems, weaknesses but also with our experience can achieve for the benefit of our patients a better future.

I wish this conference to mark the beginning of a successful and fruitful cooperation.

The Diseases and their cure have no frontiers.

Thank you for inviting me and for your attention.

Now I would like to show you some pictures of the latest event I mentioned before.





















