

Report EULAR Country Visit to support Macedonian (F.Y.R.) campaign for the implementation of EULAR`s Brussels declaration.

Attendees:	<p>EULAR president elect Maurizio Cutolo</p> <p>EULAR Vice president representing PARE Neil Betteridge</p> <p>EULAR General Secretary Nemanja Damjanov</p> <p>EULAR Chair SC PARE Jacqueline Mäder</p> <p>EULAR PARE Board members</p> <p>Representatives of EULAR PARE Youth group</p> <p>EULAR secretariat: Florian Klett and Birte Glüsing</p>
Event:	<p>Political and public event</p> <p>Meeting with high national officials and subsequent press conference followed by a scientific lecture</p>
Theme of the event:	<p>Campaign launch for the implementation of the</p> <p align="center">National platform for development of rheumatology "- Macedonian (F.Y.R.) campaign for the implementation of EULAR`s Brussels declaration.</p>
Organised by:	<p>Organised by Macedonian (F.Y.R.) patient organisation NORA (Nongovernmental Organization for Rheumatism and Arthritis) in cooperation with EULAR</p>
Date:	<p>17 June 2011</p>

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SUMMARY

Objectives

The event around the “launch of the national platform to develop rheumatology” pursued three main objectives:

- To **present and discuss innovative approaches** in the management of Rheumatic Diseases, particularly on prevention, disease management, patient involvement and equal access to care
- To **raise awareness** among decision makers from the Macedonian (F.Y.R.) and the general public about how Rheumatic diseases impact the economic wellbeing of a society but also how these diseases impact on the society as a whole
- To **gain support** by the Macedonian (F.Y.R.) institutions and policy makers and to respond to the challenges posed by rheumatic diseases.

Audience

The conference was particularly targeted to the following groups:

- Policy makers
- People with musculoskeletal diseases and other chronic conditions
- Scientific community
- Public in general

Outcomes - projected

The main messages to convince the governmental authorities and public authorities centred on:

- Prevention of the diseases
- Early diagnosis
- Optimization of treatment options available on the national level
- Empowerment of patients through self management
- Promotion of NGO NORA to become an ally and partner in developing a national strategy on rheumatic diseases

Outcomes realised

- The president of Macedonia (F.Y.R.), Mr. Gjorgje Ivanov, sent a letter stressing the need for cooperation between countries for improvement of the situation of patients with rheumatic and musculoskeletal diseases. The recommendations from the "Brussels declaration "is a good step forward for greater quality of life for patients".
- NGO NORA positioned itself as a source of expertise willing to collaborate and to cooperate with all stakeholders present to tackle issues at hand. NGO NORA became a "public interest organisation". The backing of EULAR and its member organisation has been shown to politicians and the public. (Information updated 9.11.2012)
- "Methotrexate has been made available without limitations thanks to the efforts of NGO NORA as per 1.1.2011" (representative National health fund)

Structure of the event

This one-day event comprised of an internal roundtable discussion and a public panel discussion.

Roundtable discussion 9:30 – 10:45:

Internal, high level meeting

"RELEVANT ISSUES IN MACEDONIAN HEALTH SYSTEM"

"National platform for development of rheumatology" - Macedonian campaign for the implementation of EULAR's Brussels declaration

During this roundtable discussion between EU representatives, National Health Fund, Health Ministry, NORA and EULAR important issues for treatment optimization of rheumatic and musculoskeletal diseases in Macedonia (F.Y.R.) have been communicated to the health institutions.

Attendees:

Mrs. Florija. L. Maloku, Cabinet of the President of the Republic

4 representatives, from the National Health Insurance Fund

Ms. Eleonora Pandilova, Bureau of Medications

Dragan Chichikj, President NGO NORA

Suzana Bozarova, Vice President NGO NORA

Laze Efremov, General secretary NGO NORA

Dr. Dubravka Antova, MAAR, Rheumatologic society

Rheumatology Clinic in Skopje, Prof. Dr. Jordan Calovski

Prof. Matija Tomsic, rheumatologist, Slovenia

All EULAR representatives

Press conference /Panel discussion 11:15 – 12:45:

IMPLEMENTATION OF THE BRUSSELS DECLARATION ON RHEUMATIC AND MUSCULOSKELETAL DISEASES

“RHEUMATIC AND MUSCULOSKELETAL DISEASES IN FOCUS OF MEDIA AND POLITICS”

Media and public relations

At the press conference and panel discussion 65 guests were present.

There were journalists from:

- National televisions: Kanal 5, MRTV(Macedonian and Albanian), Alfa, Sitel, AB channel, A1, Kurir, 24 News
- News agencies – MIA and MAKFAX (the only two news agencies in Macedonia)
- Newspapers – Vecer
- Radio – Macedonian National Radio (MRTV)

Also internet news portals published news about the events on 17th June: www.plusinfo.mk, www.tocka.com.mk, www.zurnal.mk

Scientific lecture by Maurizio Cutolo 13:15 – 15:15: Prof Cutolo held a lecture to the interested audience of practicing rheumatologists in Macedonia (F.Y.R.). Lecture topics:

- The everyday neuroimmunoendocrine risk factors and autoimmune rheumatic diseases”

- “The links between the circannual low vitamin D and rheumatic diseases “
- "Optimization for the use of glucocorticoids after their first 60 years"

Before 17 June - Preparation and media work

NGO NORA appeared on state television on two occasions. The report of a visit by authorities to NGO NORA's offices can be found at the end of this document in Appendix 1.

Prearranged interviews were published

- Neil Betteridge in www.globusmagazine.com.mk
- Jacqueline Mader in Kompletna – magazine
- Maurizio Cutolo in VOX magazine for doctors

Media - Follow Up*

Interviews were taken during 17 June with Neil Betteridge, Matija Tomcic, Dragan Chichikj, Florija Moloku, Jordan Calovski, Branko Adzigogov.

After the event NORA got 4 invitations from national televisions, to be guests in TV shows regarding the events that happened on 17th June.

STATEMENTS

Dragan Chichikj President – “NORA” said that there are 40,000 people with rheumatic and musculoskeletal diseases and the implementation of the recommendations of the "Brussels Declaration on rheumatic and musculoskeletal diseases" would be overwhelming support for dealing with these diseases.

"That is why we are proud that first in Europe we are starting this campaign for implementation of the recommendations of the "Brussels declaration". For Macedonia (F.Y.R) is particularly important to popularize the field of rheumatology, to recognize the importance of the socioeconomic impact of rheumatic and musculoskeletal diseases, to ensure the right of patients to participate fully in society and patients access to high-quality care."

Prof. Maurizio Cutolo, EULAR president - elect, noted the importance of education for patients, doctors and health professionals.

"Education is the right way to improve the situation of rheumatic and musculoskeletal diseases. Symptoms should not be covered, because in that way the disease is disguised and it'll come to a stage when it is too late to react properly. Early diagnosis along availability of

new treatments remains essential. Primary prevention for Macedonia (F.Y.R) is also very important. There has to be a proper optimization of medications."

Prof. Nemanja Damjanov, EULAR General Secretary, compared the situation in Macedonia (F.Y.R) with the situation in Serbia which is now much improved for patients. He said that funds have to be redistributed.

"You should invest in early diagnosis of rheumatic and musculoskeletal diseases and health institutions in Macedonia (F.Y.R) are those who need to help in solving the problems of patients."

Ms. Jacqueline Mäder, Chairperson of the Standing Committee of PARE, and also a patient - diagnosed with osteoarthritis, stressed the need for strong cooperation between all member organizations of EULAR.

"We should have the same goal to speak with one strong voice in Europe. Inclusion of organizations - members of EULAR is essential. It is good that in Macedonia (F.Y.R) there is support from the institutions in health, because it means that patients have a greater chance for a better quality of life."

Mr Neil Betteridge Vice President EULAR - PARE from UK stressed that Macedonia (F.Y.R.) has the chance to learn from many of the organizations in Europe and vice versa.

"Patients are those who are true experts on their illnesses, because they live with symptoms for many years and their opinions are important for improving treatment. In Europe the situation is not perfect, but patients have their rights and we must not leave them on the margins of society. I think that it is important for Macedonia (F.Y.R.) to have "National Strategy" for dealing with these diseases, and the "National Platform" of "NORA" is a good beginning, and it should be supported by health institutions, and the government."

Prof. Dr. Jordan Calovski, director of the Rheumatology Clinic explained that a major problem is that there are not enough specialists who treat these diseases, but for this purpose there are a lot of educational training seminars and there is hope for improvement of the situation. In further collaboration with EULAR and NORA we will try to make the right decisions for patients.

The National Insurance Health Fund and the Bureau of Medications also support patients in their fight for better quality for life. Changes are needed so patients can have better treatment, and in the future plans optimization of medications will be made.

Links available from published material:

<http://sitel.com.mk/dnevnik/makedonija/okolu-1500-deca-stradaat-od-revmatski-zabолuvanja>

http://mtv.com.mk/mk/vesti/ticker.css/17626/briselska_deklaracija_za_revmatoloski_i_muskuln_oskeletni_zabолuvanja.aspx

<http://vecer.com.mk/?ItemID=1A4368F96F975146B746EEBC430BF2E2>

<http://www.plusinfo.mk/vest/5217/Nora-prva-vo-Evropa-so-implementacija-na-Briselskata-deklaracija-za-revmatski-arthritis>

<http://www.plusinfo.mk/vest/5349/Gruevski-ne-posveti-vreme-za-bolnite-od-revmatoiden-arthritis>

<http://www.tocka.com.mk/index15.php?ID=43973>

<http://zurnal.mk/content.asp?id=2011617134055>

http://makfax.com.mk/tools/refinedSearch#2%2F259768%2Fpacientite_so_revmatski_bolesti_kje_dobijat_podobar_tretman

<http://www.mia.com.mk/default.aspx?mId=35&vId=84645355&lId=1&title=%D0%9C%D0%90%D0%9A%D0%95%D0%94%D0%9E%D0%9D%D0%98%D0%88%D0%90+-+%D0%97%D0%94%D0%A0%D0%90%D0%92%D0%A1%D0%A2%D0%92%D0%9E>

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APPENDIX 1 - REPORT MEETING NGO NORA , MINISTRY OF HEALTH & HEALTH FUND

Meeting in NORA (Non - governmental Organization for Rheumatism and Arthritis) with Deputy Minister of Health - Prof. D-r Vladimir Popovski and Director of the Health Fund of RM - Ms. Maja Paranardzhieva Zmejkova on 19th of May, 2011 at 12.00h.

Due to the recent positive changes in the field of rheumatology and Rheumatology Clinic in Skopje, we (NORA) held a meeting with Deputy Minister of Health - Prof. D - r Vladimir Popovski, Director of the Fund for Health of RM - Ms. Maja Paranardzhieva Zmejkova.

On May 19, Thursday at 12.00 am, Director of the Health Fund - Ms. Maja Paranardzhieva Zmejkova and Deputy Minister of Health - Prof. D - r Vladimir Popovski visited the office of NORA. The purpose of this visit was to discuss the positive developments in the field of rheumatology and to continue the fruitful cooperation for the good of the patients.

What matters most now for rheumatology patients is that the budget of the Clinic for Rheumatology has increased by 50% which can be treated more severely ill 70 patients with biological therapy. For successful treatment of patients The Health Fund will publish the guidelines for treatment in the Law Journal, in which case they will be legalized. The guidelines for treatment are currently in the process of approval by an international institution.

With further cooperation we will present the "Platform for the development of rheumatology in Macedonia" as part of the launch of the campaign for the implementation of the " Brussels Declaration on muskuloskeletal and rheumatic diseases". The campaign for the implementation of the "Brussels Declaration", will begin with a visit from European Delegation, EULAR (European league against rheumatism and arthritis), where NORA is a member since 2009.

"I am honored in such a nice day to have such a positive informative meeting. We found solutions for many things for which we have fought in the past three years. The first is the introduction of the guidelines for treatment of rheumatoid atritis that, as promised by the Health Fund, will come out in the Law Journal next week. This will cover all patients, the first-stage diagnosis and the ultimate therapeutic treatment. The second is the "National Platform" on the rights of patients, rehabilitation, proper diagnosis and the third is that our association will publish a platform for the development of rheumatology in Macedonia. We will not allow discrimination. Now the most severely ill patients are receiving biological therapy, further the number of patients who will be on biological therapy will increase gradually. For us as NORA it is very important that the time comes to launch the campaign for the introduction of the "Brussels Declaration", which will actually be improving of the conditions and rights of patients. The arrival of the European delegation from EULAR is a step forward and it unites forces for a better exchange of information and also creates better living conditions for patients"- said Dragan Chichikj, President of NORA.

"I would like to praise the efforts of NORA in the battle for improvement of health services. NORA first identifies the problems and then defines steps that can be further supported and realized. Draft guidelines for treatment for treating patients with rheumatic diseases are currently given for an international approval, soon they are going to be published in the Law Journal of the Republic of

Macedonia, in which case they will be legalized. The guidelines for treatment exemplify the standard of work and it's really important for patients. Also, with the budget allocation to all health facilities, The Health Fund on April the 1st, increased the budget of the clinic by 50 percent, respectively from 45 to 65 million denars as an opportunity to increase health services in Macedonia "- said Parnardzieva - Zmejкова, director of the national health fund.

"Thanks to NORA initiative, efforts are made in order to finalize the guidelines for treatment which will facilitate the determination of therapy for patients. Until now rheumatology guidelines for treatment were not adopted, this is a step forward and evidence that the rights of patients to modern therapy, based on evidence, will be guaranteed. The increase of the budget of the Clinic of Rheumatology for 50% is a significant step forward in ensuring the availability of biological therapy. And the moment of arrival of the European delegation of EULAR for us is just an incentive for proper organization in the European approach of treating patients. I am a part of the coordinating body for the promotion of rheumatology in Macedonia together with NORA and the Ministry of Health. All of these joint activities will contribute this very widespread disease to be brought under control in our country following modern guidelines for treatment and thus enable the improvement of quality of life for these patients" - said Prof. D- r Popovski

The main message of NORA, is that the impact of these chronic diseases is enormous and growing, more than 120 million people in Europe suffer from rheumatic and muskuloskeletal diseases and the budget of the EU countries spends 240 billion euros annually because of disability, early retirements, hospital costs and costs for drugs.

Recommendations adopted at the Conference in 2010 are formulated in the "Brussels Declaration", which is to be implemented in member states of Europe to improve the situation as regards to muskuloskeletal and rheumatic diseases. To solve the problems that brings rheumatic diseases, NORA along with EULAR, will be the first in Europe to begin a national campaign for the implementation of the "Brussels Declaration".

This information was published in the following media on the same day:

On television: Alfa Tv, Sitel Tv, Kanal 5 Tv.

In the newspapers: Dnevnik, Utrinski, Vecer.

On internet portals: www.idividi.com.mk, www.zurnal.mk, www.tocka.com.mk.

In news agencies: MIA and Makfax.