

Report EULAR Country Visit to support BOPRD (Bulgarian Organisation of People with Rheumatic Diseases) campaign for the implementation of EULAR's Brussels declaration.

Attendees EULAR:	<p>EULAR Vice president representing PARE Neil Betteridge</p> <p>EULAR Chair SC PARE Maria Batziou</p> <p>EULAR Chair-elect David Magnusson</p> <p>EULAR PARE Board member Diane Skingle</p> <p>EULAR PARE Board member Codruta Zablan</p> <p>EULAR secretariat: Florian Klett and Birte Glüsing</p>
Event:	<p>Political and public event</p> <p>Public Awareness Raising event; Roundtable discussion with high national officials, Member of European Parliament; Signage of Brussels declaration; media interviews; scientific lecture</p>
Theme of the event:	<p>Campaign launch for the implementation of the</p> <p>Life and treatment of people with rheumatic & musculoskeletal diseases in Bulgaria</p>
Organised by:	<p>Organised by BOPRD (Bulgarian Organisation of People with Rheumatic Diseases) in cooperation with EULAR</p>
Date:	<p>29 June 2012</p>

CONTENTS

Summary	2
Objectives.....	2
Outcomes - projected.....	3
Outcomes realised.....	3
Structure of the event	3
Statements	5
Links available from published material	6
Further Information / Assistance	7
Appendix 1 - report meeting NGO NORA , Ministry of Health & Health Fund	8

SUMMARY

Objectives

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

- To **present BOPRD as equal partner in national healthcare issues** related to chronic diseases to the healthcare institutions, policy makers and the media.
- To **build alliances** to tackle the challenges in healthcare for people with chronic diseases
- To **present and discuss innovative approaches** in the management of RMDs, particularly on prevention, disease management, patient involvement and equal access to care
- To **raise awareness** among decision makers in Bulgaria 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

Audience

The conference was particularly targeted to the following groups:

- Media
- Policy makers and healthcare institutions
- People with RMDs and other chronic conditions
- Scientific community

Outcomes - projected

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

- Promotion of BOPRD to become an ally and partner in offering solutions and tackling challenges on RMDs
- Optimization of treatment options available on the national level
- Clarification of the important role of user-led organisations in process of improving national healthcare of patients.

Outcomes realised

- Awareness about RMD's was raised.
- BOPRD is recognized as an significant partner in most of the issues connected to RMD's

Structure of the event

This one-day event comprised of two lectures on RMDs and a public roundtable discussion.

Scientific lectures

13:00 – 13:20

Dr Mariana Ivanova, Rheumatologist in University hospital "St. Ivan Rilski"

Ankylosing spondylitis and rheumatoid arthritis – social importance, clinical aspects and therapeutical strategies

13:20 – 13:40

Assoc. Prof. Dr Troicho Troev, Head of the Physiotherapy Clinic of The Military Hospital

Improving the quality of life for people with RA by means of physiotherapy

Roundtable discussion 13.45 – 16:45:

High level meeting

"LIFE AND TREATMENT OF PEOPLE WITH RHEUMATIC & MUSCULOSKELETAL DISEASES IN BULGARIA"

BULGARIAN LAUNCH OF EULAR'S BRUSSELS DECLARATION CAMPAIGN

During this roundtable discussion between Member of the European Parliament, the Bulgarian Ombudsman, Health Ministry, [Bulgarian Medical association](#), Bulgarian Patient Umbrella Association, Bulgarian State Military Hospital , [National specialized hospital on physiotherapy and](#)

[rehabilitation](#), BOPRD and EULAR important issues for treatment optimization of rheumatic and musculoskeletal diseases in Bulgaria have been communicated, common challenges identified and offers for alliances and partnerships have been expressed between important stakeholders.

Attendees:

All EULAR representatives

Ivaylo Kalfin, MEP for Social and Economics

Tsveta Apostolova, President BOPRD

Boryana Boteva, Vice President BOPRD

Bulgarian Ombudsman

[Dr Dimitar Lenkov, General Secretary of Bulgarian Medical association](#)

Dr Stoicho Katsarov, President of the Centre for Healthcare rights

[Assoc. Prof. Dr. Troicho Troev](#), Head of the Physiotherapy Clinic of The Military Hospital

[Dr Mariana Ivanova](#), Rheumatologist in University hospital “St. Ivan Rilski”

[Dr Maria Stoicheva](#), National specialized hospital on physiotherapy and rehabilitation, Sofia

[Assoc. Prof. Dr. Bojidar Ivkov](#), sociologist

Ministry of Health

[Members of Bulgarian ankylosing spondylitis ssociety](#)

Media and public relations

At the roundtable discussion 50 guests were present.

There were journalists from:

- [National newspapers](#)
- [National tv channels](#)
- [Web \(internet\)media](#)

Also internet news portals published news about the events on 29th June

Before 29 June - Preparation and media work

BOPRD appeared on state television. A small summary can be found at the end of this document in Appendix 1.

Interviews were conducted during 29 June

- Neil Betteridge
- Boryana Boteva

Media - Follow Up*

After the event BOPRD got XYZ invitations from ...

STATEMENTS

Boryana Boteva, Vice President BOPRD stated that that for more than 100000 people with RMDs in Bulgaria the implementation of the recommendations of the "Brussels Declaration on rheumatic and musculoskeletal diseases" would mean concrete attentions for the issues of and direct improvements for the lives of people with these diseases.

"Access to quality social services and health care, is an important topic which needs to be discussed in a group of equal partners to create, plan and implement improvements in the Social services and health care sector in Bulgaria."

The Bulgarian Ombudsman stated that all people are patients and no one is excluded or a different group of people. Hence receiving the most effective treatment

"should be a right, not a privilege, and working together in partnership between stakeholders present can achieve important steps towards being able to reach this objectives"

Dr. Stoicho Katsarov, President of the Centre for Healthcare rights explained the lack of access to treatment, to specialists and the reasons for the structural deficiencies in health care and limited options for people with RMDs.

Statement

Moderator of the day and representative of patient associations in Bulgaria asked for support because the situation for people with chronic diseases in Bulgaria is very dire.

"The Patient association is helping people with chronic diseases to survive, but this should be the job of the health care system"

Member of European Parliament Ivaylo Kalfin

Structural problems in Bulgaria which need to be addressed, he expressed full support in making changes happen in the future regarding the new funding program (Horizon 2020) and the availability in the future for BOPRD to be contacted.

Neil Betteridge EULAR Vice president, representing PARE emphasised that

“The challenges are so great that they can only be overcome if everyone involved is working together, at the organisational level, health professionals and institutions with organisations like BOPRD, but also on the individual level to find one strong voice to make positive changes happen in society”

Dr. Maria Stoicheva, Representative of specialised rehabilitation clinic offered to unite the efforts

LINKS AVAILABLE FROM PUBLISHED MATERIAL

Links available from published material:

<http://www.europe.bg/bg/htmls/page.php?category=374&id=39614>

<http://www.vesti.bg/index.phtml?tid=40&oid=4938071>

<http://www.focus-news.net/?id=n1670531>

<http://tv7.bg/news/bulgaria/9356592.html>

- EULAR Executive Secretariat

Florian Klett
Project Coordinator
Seestrasse 240
CH-8802 Kilchberg
Switzerland
Direct T +41 44 716 30 35
Direct_F +41 44 716 30 39
Florian.klett@eular.org

- EULAR Executive Secretariat

Birte Glüsing
Project Manager
Seestrasse 240
CH-8802 Kilchberg
Switzerland
Direct T +49 22 89 62 12 83
Direct_F +49 22 89 62 12 84
birte.gluesing@eular.org

- BOPRD Bulgarian Organisation of People with Rheumatic Diseases

Tsveta Apostoleva, President
Boryana Boteva, Vice President
Bulgarian Organisation for Patients with Rheumatic Diseases
Dianabad 9-5-20
1172 Sofia
Republic of Bulgaria
revmatologia.org@gmail.com
<http://blog.revmatologia.org/>

- EULAR EU Office

Avenue des Arts 39
1040 Brussels/Bruxelles
Belgium
T +32 2 513 7702
F +32 2 502 7703
brussels@eular.eu

