NATIONAL ALLIANCE FOR RARE DISEASES OF R. MACEDONIA

ВИЛСОН МАКЕДОНИЈА

LIFE with CHALLENGES

EUROPLAN
European Project for Rare Diseases National Plans Development

Republic of Macedonia

EUROPLAN NATIONAL CONFERENCE

in the framework of the EU Joint Action RD-ACTION

Skopje, 10/11/2017

FINAL REPORT

RD ACTION
DATA AND POLICIES FOR RARE DISEASES

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EURORDIS
RARE DISEASES EUROPE

FOREWORD

The EUROPLAN national conferences or workshops are organised in many European countries as part of a coordinated and joint European effort to foster the development of comprehensive National Plans or Strategies for Rare Diseases addressing the unmet needs of patients living with a rare disease in Europe.

These National Plans and Strategies are intended to implement concrete national measures in key areas from research to codification of rare diseases, diagnosis, care and treatments as well as adapted social services for rare disease patients while integrating EU policies.

The EUROPLAN national conferences/ workshops are jointly organised in each country by a National Alliance of rare disease patients' organisations and EURORDIS–Rare Diseases Europe. **Rare Disease National Alliances and Patient Organisations have a crucial role to shape the national policies for rare diseases.**

The strength of EUROPLAN national conference/ workshop lies in its shared philosophy and format:

- **Patient-led**: National Alliances are in the best position to address patients' needs;
- **Multi-stakeholders**: National Alliances ensure to invite all stakeholders involved for a broad debate;
- **Integrating both the national and European approach to rare disease policy;**
- **Being part of an overarching European action** (project or Joint Action) that provides the legitimacy and the framework for the organisation of EUROPLAN national conferences/workshops;
- **Helping national authorities adhere to the obligations stemming from the Council Recommendation of 8 June 2009 on an action in the field of rare diseases.**

Since 2008, National Alliances and EURORDIS have been involved in promoting the adoption and implementation of National Plans and Strategies for rare diseases. Altogether, 41 EUROPLAN national conferences took place in the framework of the first EUROPLAN project (2008-2011) and the EU Joint Action of the European Committee of Experts on Rare Diseases – EUCERD - (2012-2015).

Within RD-ACTION (2015-2018), the second EU Joint Action for rare diseases, National Alliances and EURORDIS continue to get involved in a coordinated European effort to advocate for and promote integrated national policy measures that have an impact on the lives of people living with rare diseases.

The EUROPLAN national conferences or workshops taking place within RD-ACTION focus on specific themes identified by the National Alliances as the most pressing priorities to tackle with national authorities. These thematic priorities are addressed in sessions where all the stakeholders discuss relevant measures to be taken or ways to sustain the full implementation of already approved measures.

Each National Alliance prepares a final report on the national workshop, based on a common format such as the one that follows.

GENERAL INFORMATION

Country	Republic of Macedonia
National Alliance (Organiser)	National Alliance for Rare Diseases of Macedonia - Skopje, NARDM Wilson Macedonia Life with Challenges
Date & place of the national workshop/conference	10 November 2017, Skopje, Macedonia
Website	NARDM: www.retkibolesti.mk Wilson Macedonia: www.wilsonorg.mk Life with Challenges: www.challenges.mk
Members of the Steering Committee	Vesna Aleksovska Anja Bosilkova Antovska Maja Aleksievska Dimikj
List of Themes addressed	1. Legislation on rare diseases 2. RD Committee and Registry 3. Diagnostics, treatment and orthopaedic aids 4. Centre for RD (incl. social services)
Annexes :	I. Programme (en) II. List of Participants (by stakeholders' categories) III. Brochure (mk) IV. Press clipping - media coverage V. Photos

FINAL REPORT

I. Introduction/ Plenary session

At the plenary session there were presentations from couple of speakers. We started with an opening speech from the president of the alliance – Rebeka Jankovska Risteski, who talked about the problems and the challenges that people with rare diseases face every day. Anja Bosilkova Antovska continued to present the situation regarding the regulation process for rare diseases in Macedonia and she emphasized the need for improvement since at this moment people with rare diseases are invisible. Vesna Aleksovska, talked about the importance of having a national plan for rare diseases and in short she presented the priorities of the proposed plan for Macedonia such as: regulation for rare diseases (including registries, treatment, medical devices), diagnosis, prevention, information, social services etc.

After that, the guests from EURORDIS and the French Alliance discussed the importance of national plans for rare diseases, and how they are implemented in the EU. The guest from the French Alliance explained

how the plan for rare diseases was developed and has been implemented in France since 2005, and its measurable impacts on improving care pathways for the patients. Furthermore, the guest speakers from the Balkan region covered several relevant topics, from national plans management to social services and awareness raising, sharing their countries' experiences (see agenda in annex I). The last part of the conference were the thematic group discussions, led by NARDM representatives, gathering many different stakeholders, including patients, to discuss the main challenges at stake and share ideas for possible solutions.

II. Themes

THEME 1: LEGISLATION ON RARE DISEASES IN MACEDONIA

Identification of specific gaps, challenges and needs: The current legislation in Macedonia does not cover almost any issues that patients with rare diseases are dealing with. The term "rare disease" is not defined explicitly in any law in the Republic of Macedonia. Rare diseases are invisible in the healthcare system due to lack of definition, appropriate coding and classification. This is also reflected in the treatment/management of rare diseases by the relevant institutions, unsuitable for addressing the challenges part of the phases of diagnosis, treatment and monitoring of rare diseases.

- **Assessment of the integration of European guidelines and policy recommendations into the national system:**

The EU definition of rare diseases laid down in the EU Regulation on orphan medicinal products (EC) No 141/2000 is used in the only legal act for regulating the procurement of medicines for registered patients with rare diseases – the Programme for rare diseases by the Ministry of Health. Based on the EC definition, the document states that a rare disease is every condition or disorder that affects only 1 in 2000 of the country population.

- **Expected outcomes in the near future, medium and long term** *(in particular the expectations from the patients and their families).*

Our goal is to initiate the necessary change in the Macedonian legal system that would ensure long term solutions and an institutionalized approach to the treatment of RD, allowing for proper treatment and improved quality of life. Thus, having in mind the recommendations of the EU Council, as well as the experience of the countries in the Balkan region, there is an urgent need for adopting a National Strategy for Rare Diseases, and furthermore developing an explicit law covering the primary aspects of this issue, namely: conditions for diagnosis, availability of drugs, monitoring systems, etc. Having a functional system in place that takes care of RD patients in the early stages will ensure more people are healthy and able to contribute to the society instead of being a burden to both the family and the state.

- **Which actions/ measures need to be taken**:

The first step to be taken is to define the main terms in this field in the Law on healthcare or other relevant laws so that they can be distinguished, further specified and legally regulated. Concrete actions that need to be taken are: adding a definition of 'rare disease' in the main laws; defining the national registry of rare diseases in the Law on Health Care, so that further criteria and rules for managing its operations can be set; defining and regulating the Committee for Rare Diseases; adopting an appropriate budget for managing rare diseases; and regulating the procurement of orphan-drugs.

THEME 2: RD COMMITTEE AND REGISTRY

- **Identification of specific gaps, challenges and needs**:

Patients with rare diseases in Macedonia have been systematically identified for the first time in 2015, when the Ministry of Health started implementing the first RD registry in the state. However, summary data (data protecting patients' privacy, yet providing important general information such as the number of patients and the currently registered diagnoses) are not available, pointing out to the lack of transparency in the work of the institutions. The only body authorized to register patients is the Commission for Rare Diseases at the Ministry of Health, however it is not subject to any legal regulation so far. Moreover, there are no clear procedures about the way it functions, starting from the selection of the Committee members, to the defining of tasks and responsibilities.

- **Assessment of the integration of European guidelines and policy recommendations into the national system:**

The developed registry was presented at conference for rare disease registry in Italy – EPIRARE and representatives from the Ministry of Health were in contact with different countries regarding improvement of the registry. For now, it is in compliance with EU guidelines. Furthermore, we expect improvement in technicalities and clear criteria and procedure for registering patients.

- **Expected outcomes in the near future, medium and long term**: *(in particular the expectations from the patients and their families).*

The involvement of patient organization representatives in the Committee's work would increase the transparency of the Committee, allowing patients to take part in decision-making through discussions and sharing the problems that they face daily. As patient organizations play a particularly important role in guiding the newly diagnosed patients through the initial period of treatment and/or counselling, it is expected that they would be more consulted and involved in the process, and the cooperation with the institutions will be taken to a higher level.

- **Which actions/ measures need to be taken**:

The management and improvement of the healthcare services for patients with rare diseases must be based on accurate epidemiological data that enable the planning of health policies in accordance with the factual situation. Therefore, the Registry needs to be carefully managed by a designated team of professionals and needs to be regularly and appropriately updated.

THEME 3: DIAGNOSTICS, TREATMENT AND ORTHOPAEDIC AIDS

- **Identification of specific gaps, challenges and needs**:

Having in mind the sporadic appearance of rare diseases, the practical experience of doctors working in this field in Macedonia is low, and so is the capacity of the entire health system in terms of recognition, diagnosis, treatment and prevention of these diseases. It takes months, or even years for patients to get a diagnosis, which is due not only to the inexperienced doctors and their inadequate or lack or expertise, but also to the inaccessibility of diagnostic measures, inadequate laboratory materials, techniques and apparatus; unsuitable conditions for monitoring the disease, etc. In the treatment of rare diseases, some patients, in addition to the therapy and regular monitoring, need diet supplements or orthopaedic aids, which are not available in Macedonia or are not reimbursed by the state, subjecting patients to many additional costs.

At this point there is great progress in cooperating with the Health Insurance Fund regarding orthopaedic devices, while also special food is refunded for patients with rare diseases such as: phenylketonuria, Allagile syndrome, cystinuria, homocystinuria, Barter syndrome, adrenoleukodistrophy Addison-Schilder, mestioninemia, deficit of sulfidic oxidase, Rett syndrome and many others. We expect that the list will be further revised taking in consideration new diagnosis and new needs that come from them. Moreover, the government plans on increasing the finances for the Programme for rare diseases so more drugs can be available for the patients.

- **Expected outcomes in the near future, medium and long term**: *(in particular the expectations from the patients and their families)*

Diagnosis to be provided and refunded for all rare diseases. If the diagnosis cannot be performed in the country, it should be made through international cooperation. Access to treatment should be provided for all rare disease patients.

- **Which actions/ measures need to be taken**:

Initially, in the coming months, it is necessary to organize a meeting where the available options for diagnostic procedures in the country will be discussed. This meeting should be attended by all diagnostic centres in Macedonia (public or private), the Health Insurance Fund and the Ministry of Health. Afterwards, the Health Insurance Fund should publish on its website information about where specific diagnostic procedures can be done (licenced laboratories with diagnostics reagents and kits) and where the costs for such procedures will be reimbursed to the patients. Finally, an important measure that needs to be adopted as soon as possible is the following – in case a diagnosis cannot be concluded in the state institutions within a legally specified timeframe (e.g. 6 months), the costs for diagnosis in a private institution in the country or in another diagnostics centre abroad should be covered by the Health Insurance Fund.

THEME 4: CENTRE FOR RD (INCL. SOCIAL SERVICES)

- **Identification of specific gaps, challenges and needs**:

Due to the small number of patients, the experience of the medical staff and the knowledge about the possibilities for prevention, diagnosis and treatment of rare diseases are insufficient. Given that most often rare diseases are complex and encompass a wide range of possible clinical conditions, in diagnosing and treating a patient, it is necessary to provide multidisciplinary access, care and coordination within different departments and the health system as a whole.

The institutions are currently discussing the development of a rare disease centre and they are consulting with rare disease organizations, which is a step forward to having at first and informational non-medical centre and then designating medical centres for different rare disease groups. Moreover, the current Minister of Health was present at the conference and had a meeting with participants from other countries to discuss best practice regarding rare disease centre.

- **Expected outcomes in the near future, medium and long term**: *(in particular the expectations from the patients and their families).*

Patients and families stress the need for establishing a specially designated institution i.e. Centre for Rare Diseases, which will enable them access to complex medical services and multidisciplinary approach to their treatment. Any patient who is in a life-threatening state and cannot be diagnosed within a reasonable period or anyone who suffers for a rare illness - should be treated in a Centre for Rare Diseases. In such an institution, a team of specialists from different areas, educated or connected to other reference centres internationally, should provide a multidisciplinary approach in diagnosis and treatment. This should be done in accordance with established national and international guidelines and protocols for treatment, as well as coordination and cooperation with other medical institutions, persons and organizations for the purpose of providing an entire service to patients.

- **Which actions/ measures need to be taken**:
  - Education of employees in centres for social care;
  - Education of psychologists and other professionals that care for people with special needs, on the specificities of rare diseases so that they can offer help and support to families and patients;
  - Designating centres of expertise (clinical centres and doctors) for different rare diseases that are already registered.

III. Conclusions

The themes were chosen based on numerous meetings and consultations with patient organizations in Macedonia and/or relevant institutions, as well as in-depth research on the current situation and management of rare diseases in the country, recently implemented by two patient organizations. Namely, in 2015, the association of citizens for rare diseases LIFE WITH CHALLENGES published a research paper about the needs of the patients and the overall situation in Macedonia in comparison with other countries in the Balkan region and EU. Later, in 2016, WILSON MACEDONIA – Association for supporting people with Wilson's disease – published a policy paper on the current legislation in Macedonia, providing policy recommendations on the necessary changes in the legal system, based on the best practices and experience of other countries in the region and in Europe.

Through the thematic working groups at the conference, as well as the previous meetings with organizations for rare diseases, the relevant institutions in Macedonia have received vast information regarding the challenges and the possible solutions through the perspective of the patients themselves. We also communicated the EU recommendations having in mind that some things that are already done in other countries could be applied in the national context. Currently, there is no national plan for rare diseases in Macedonia and the only legal act regarding the management of rare diseases is the Program for Rare Diseases of the Ministry of Health, with the main purpose of providing medicines for the registered patients. However, this program needs many improvements, mainly in terms of rules and criteria within the programme, the transparency of the process needs to be enhanced, and the registry of patients and diseases needs to be promoted and implemented better through gathering information from all hospitals and clinical centres throughout the country. In addition, the government has announced its plans to establish a national centre for rare diseases and consultations have been organized to gather feedback from patient organizations.

We expect to further develop the draft national plan with all stakeholders and then continue with campaign to adopt the plan and a budget for its implementation. In the first two month after the conference we will again consult with all stakeholders, engage an expert consultant to review and adjust the plan, and after a draft national plan is finalized, the document shall be signed by all organizations, as well as doctors, researchers, and other stakeholders, and will be delivered to all institutions. After that, we will continue advocating and lobbying for adoption and, afterwards, proper implementation of the plan. Rare disease day in 2018 will be focused on what we have achieved from the plan and what measures and action need to be taken further to improve quality of life of patients with rare diseases.

ANNEX I – AGENDA OF THE CONFERENCE

EUROPLAN CONFERENCE MACEDONIA – Long-Term Solutions for Rare Diseases

***„Together we are building a future for people with rare diseases "*- 10 November, Holiday Inn, Skopje**

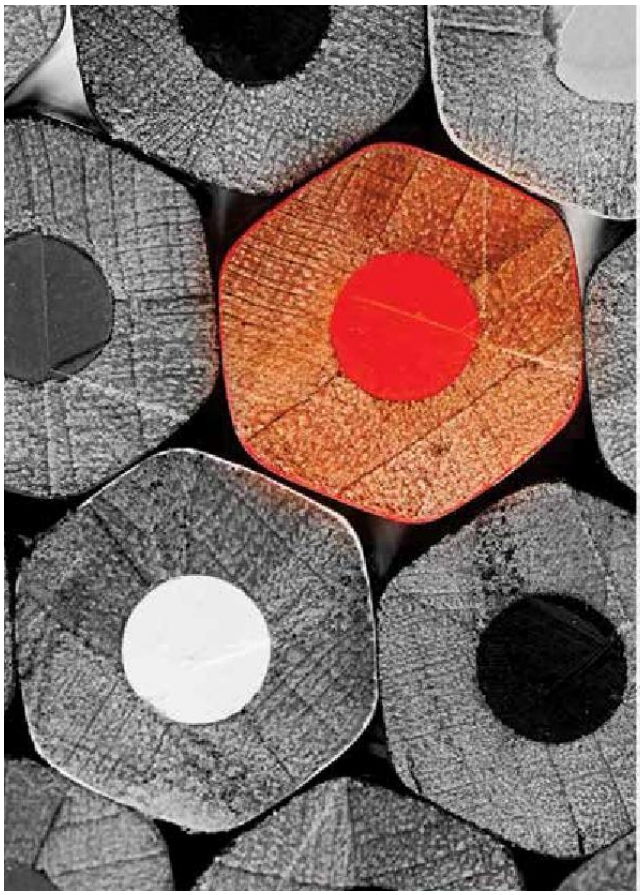
10.00 - 10.10	**Opening speech**	
	Rebeka Jankovska-Risteski, NARDM	Introduction
10.10 - 10.30	**Rare Diseases in Macedonia: Problems and Solutions Needed**	
	Anja Bosilkova Antovska, WILSON MACEDONIA	Regulative on rare diseases in Macedonia
	Vesna Aleksovska, LIFE WITH CHALLENGES	Draft national plan for rare diseases in Macedonia
10.30 - 11.30	**Experience and Best Practices from EU and the Region**	
	Ariane Weinman, EURORDIS	EUROPLAN Project in EU Countries: Why are National Plans Important?
	Marie-Pierre Bichet, French Alliance for RD	Achievements of the French National Plan for Rare Diseases: Methodology, Monitoring, and Governance of National plans
	Davor Duboka, National Alliance for RD - Serbia	Progress in Rare Diseases in the Past 5 Years in Serbia
	Sanja Peric, National Alliance for RD - Croatia	Help-Line for Patients and Families with RD
	Vlasta Zmazek, Debra Croatia	Social Innovation Care
	Vlado Tomov, National Alliance for RD - Bulgaria	Center for Rare Diseases / Progress Made with the National Plan
	Borislav Djurikj, Association for rare diseases, Bosnia and Herzegovina	Progress in Rare Diseases in the Past 5 Years in BiH
11.30 - 11.45	**Coffee break**	
11.45 - 12.45	**Working Groups on RD Priorities in Macedonia**	
	Subject	Main participants*
	1) Regulative for rare diseases in R. Macedonia	Commission for health – Parliament of R. Macedonia, Government of R. Macedonia, Ministry for finance
	2) Commission for rare diseases and registry for rare diseases	Ministry of health, Commission for rare diseases of R. Macedonia
	3) Diagnosis and treatment (drugs, supplements, orthopaedic devices)	Macedonian Academy for Science and Art, Health Insurance Fund, Agency for Drugs
	4) Centre for rare diseases, social services	Ministry for labour and social policy
12.45 - 13.30	**Presentations from work groups and discussion**	
13.30 - 13.45	**Conclusions**	
13.45 - 14.30	**Cocktail lunch**	

*The work groups are just a preposition; the representatives can choose where to participate. Participants from patient organizations will be also included in the work groups. Each group will have a facilitator.

ANNEX II – PARTICIPANTS

Number of participants	Institution/organization/company
3	Ministry of Health
3	Ministry of Labour and Social Policy
2	Agency for medicines
3	Health Insurance Fund of Macedonia
3	Commission for rare diseases (doctors)
2	Commission for health at the Assembly of Macedonia
1	Government (advisor of prime minister for health)
6	Doctors
2	Organizations from EU
15	Organizations from the Balkan region (Bosnia and Herzegovina, Serbia, Croatia, Bulgaria)
30	Organizations from Macedonia, patients, parents
10	Representatives from pharmaceutical industry

ANNEX III – **BROCHURE** (in Macedonian language)



Според дефиницијата на Европската Унија, ретки болести се оние болести кои се јавуваат кај најмногу 5 на 10 000 луѓе. Се смета дека има помегу 5000 до 8000 различни ретки болести од кои се засегнати околу 29 милиони луѓе во Европската Унија, додека во моментов во Македонија има регистрирано над 400 пациенти, но се претпоставува дека бројката ќе достигне околу 2000 пациенти. Регистрирани во Македонија се над 40 основни дијагнози, но таа бројка секако ќе стигне до 100 и повеќе со подигнувањето на јавната, институционалната и стручната свест во Македонија.

Ретките болести претставуваат клинички хетерогена група и поединечно претставуваат многу мал процент од целокупната популација, но како група тие претставуваат значаен процент во однос морбидитетот, морталитетот и квалитетот на живот на граѓаните. Задоцнетото и неадекватно препознавање и поставување на дијагноза на ретки болести често водо до трајни оштетувања, со големо влијание и врз социјалниот и финансиски статус на семејството, а неретко доведува и до смрт на заболените.

Најзначајните предизвици во пристапот и справувањето со ретки болести во земјата се: неадекватно препознавање, недоволна достапност на дијагностички ограничени терапевтски можности, неедначок и неповолен квалитет на здравствена заштита, висока цена на лечење и нега, негативни последици и изолација и маргинализација на заболените од ретки болести. Во Македонија не постои стандардизиран пристап за ретки болести, а присутна е и недоволно развиена свест на општата и стручната јавност за значењето на ретките болести и нивното влијание врз здравјето и квалитетот на живот.

Затоа е потребен национален план за ретки болести кој вклучува цели и конкретни мерки за унапредување на третманот на ретките болести во Македонија. Целта на вакивот план е поставување основа за формирање на институционална рамка и соодветни механизми за обезбедување навремена превенција, дијагноза, континуирани и квалитетна терапија, во насока на подобрување на квалитетот на живот на заболените од ретки болести и нивните семејства во Македонија.

ПРИОРИТЕТИ ВО ОБЛАСТА НА РЕТКИ БОЛЕСТИ ВО МАКЕДОНИЈА

ИНСТИТУЦИОНАЛНА РАМКА ЗА РЕТКИ БОЛЕСТИ
- Законско регулирање на ретки болести
- Национален регистар за ретки болести
- Комисија за ретки болести
- Референтен национален центар за ретки болести

ДОСТАПНА И КВАЛИТЕТНА ЗДРАВСТВЕНА ЗАШТИТА НА ПАЦИЕНТИТЕ СО РЕТКИ БОЛЕСТИ
- Унапредување на превенција и дијагноза на ретки болести
- Унапредување на контрола и мониторинг на третманот на ретки болести
- Подобрување на пристап до третман на пациентите со ретки болести
- Ортопедски помагала и поддршка за пациенти со ретки болести со попреченост

СОЦИЈАЛНИ УСЛУГИ ЗА ЛИЦА ЗАСЕГНАТИ ОД РЕТКИ БОЛЕСТИ
- Препознавање на ретки болести како социјална категорија
- Промоција на интегриран пристап кон ретки болести и социјално вклучување на пациентите со ретки болести и нивните семејства

УНАПРЕДУВАЊЕ НА ЗНАЕЊЕ И ПРИСТАП ДО ИНФОРМАЦИИ ЗА РЕТКИ БОЛЕСТИ
- Унапредување на знаење и професионални капацитети на медицинските професионалци во полето на ретки болести
- Воспоставување на ефикасна регионална и интернационална соработка
- Стимулација за истражувања на поле на ретки болести
- Организирање на национални јавни кампањи за подигнување на јавната свест за ретките болести

СОРАБОТКА СО ОРГАНИЗАЦИИ НА ПАЦИЕНТИ
- Поддршка и соработка со невладини организации на пациенти во област на ретки болести

Алијансите за ретки болести и организациите на пациентни имаат клучна улога во оформувањето на националните политики за ретки болести. Во рамките на Европската акција за Ретки Болести, ЕУРОРДИС и националните алијанси продолжуваат активно да се инволвираат во координиран Европски напор за застапување и промовирање на интегрирани национални политички и законски мерки кои имаат импакт на животите на луѓето и семејствата кои се соочуваат со ретки болести.

ЕУРОПЛАН - Европскиот проект за развој на национални планови за ретки болести (http://www.europlanproject.eu) е проект кофинансиран од Европската Комисија за промовирање и имплементација на Национални планови или стратегии за справување со ретки болести. Истиот служи за размена на релевантни искуства помегу земјите во Европа, за поврзување на национални напори со заедничка стратегија на Европско ниво за подобрување на квалитетот на живот на луѓето со ретки болести. Главната цел е да се воспостави интернационална и интерактивна мрежа на заинтересирани страни за да се забрза процесот на имплементација на Национални планови за ретки болести, преку активно учество на здруженијата на пациенти и алијансите на ретки болести заедно со ЕУРОРДИС.

НАЦИОНАЛНАТА АЛИЈАНСА ЗА РЕТКИ БОЛЕСТИ НА Р. МАКЕДОНИЈА е основана во 2014 година со цел поттикнување и поддршка на реформи во здравственот систем во областа на ретките болести во Македонија, со цел да се реши проблемот со третманот и континуираното финансирање на лекувањето на ретките болести. НАРБМ ја започна иницијативата за создавање на национална стратегија за ретки болести, која ќе овозможи долгорочни решенија за проблемите и предизвиците со кои се соочуваат пациентите и нивните семејства, и се застапува за воведување истата. Денес, членки на НАРБМ се 14 организации кои претставуваат повеќе од 70 различни ретки болести. НАРБМ е секогаш отворена за нови членки кои ја следат истата визија - овозможување надобар можен квалитет на живот за луѓето и семејствата кои се соочуваат со ретки болести.
Контакт: **retkibolesti@gmail.com** | Facebook: **https://www.facebook.com/NARBMakedonija**

ЖИВОТ СО ПРЕДИЗВИЦИ е здружение чија визија е постигнување на надобар можен квалитет на живот на пациентите и семејствата со ретки болести преку најдобри можни и достапни социјални и здравствени услуги. За да ја остварите визијата започнавме со активности за подигнување на јавната и институционалната свест со кои продолжуваме секоја година, постигнувајќи огромна поддршка при застапување и лобирање за правата на оваа група на пациенти и семејства. Нашата мисија е креирање на решенија и политики и спроведување на активности за подобрување на квалитетот на живот на пациентите и семејствата со ретки болести.
Веб страна: **http://challenges.mk/** | YouTube: **https://www.youtube.com/user/lifewithchallenges** | Facebook: **https://www.facebook.com/LifeWithChallengesi** | Twitter: **https://twitter.com/ZivotPredizvici**
ЖИВОТ СО ПРЕДИЗВИЦИ е полноправен член на

ВИЛСОН МАКЕДОНИЈА е здружение на граѓани со основна цел подобрување на квалитетот на живот на пациентите со ретки болести во Македонија и унапредување на здравствената заштита на овие лица. Главните цели на здружението се обезбедување на потребните услови за рано дијагностицирање и правилно следење на текот на Вилсоновата болест, унапредување на нивото на стручност на медицинскиот персонал за идентификација, дијагностицирање и следење на оваа болест, градење на системи за поддршка на лицата со Вилсонова болест и нивните семејства, како и соработка со слични организации од Македонија, регионот и пошироко. Активностите на Вилсон Македонија не се фокусирани само на пациентите со Вилсонова болест - здружението се залага и активно работи на подигнување на свеста во стручната и пошироката јавност за ретките болести воопшто, како и застапување на правата и интересите на пациентите со ретки болести пред институциите и донесувачите на одлуки.
Веб страна: **http://wilsonmk.org/** | Facebook: **https://www.facebook.com/wilsonmk.org/** | Youtube: **http://bit.ly/2isTL75**

Оваа конференција е поддржана од Европската Унија во рамки на проектот „Граѓаните во собранието: законодавни иницијативи за човекови права" што го реализира Фондацијата за демократија на Вестминстер во соработка со Високата школа за новинарство и за односи јавноста

Конференцијата се организира со помош на грант доделен преку проектот „Медиумска писменост во ера на наплив на информации: Коалиција за медиумска писменост", што го спроведуваа Високата школа за новинарство и за односи со јавноста во соработка со Институтот за различности во медиумите од Лондон и весникот „Нова Македонија" со финансиска поддршка од Европската Унија

Дополнителни информации за **ретки болести** може да најдете и на:
Ден на ретки болести - **http://www.rarediseaseday.org/**
Мрежа за ретки болести - **https://www.rareconnect.org/en**
Портал за ретки болести и лекови сираци - **http://www.orpha.net**
ЕУ Комитет на Експерти за Ретки Болести - **http://www.eucerd.eu/**
Европска платформа за Регистри за Ретки Болести - **http://www.epirare.eu/**
Европска Агенција за Лекови - **http://www.ema.europa.eu/ema/**
Европски Проект за Развој на Национални Планови за Ретки Болести - **http://www.europlanproject.eu**

ANNEX IV – **PRESS-CLIPPING**

Source: Internet-online services of national TV houses, daily newspapers, weekly magazines, news portals
Language of original articles: Macedonian

Source and title of news	Brief information and link
Sitel Conference for rare diseases in MASA	The Macedonian Academy of Sciences and Arts organized today the sixth conference for rare diseases. The conference is aimed at pediatricians, internists, neurologists, nephrologists, doctors of family medicine, geneticists, biochemists, biologists, medical doctors from Macedonia and South-East Europe link to source
24 Vesti The patients with rare diseases complained that they do not have enough medicines and treatment	There aren't enough medicines for patients with rare diseases, the treatments are late for months because of tender procedures and each delay of treatment is a dangerous threat to their lives - complained the associations of people with rare diseases. link to source
Alsat Rare diseaes, medicines needed for patients	People with rare diseases should not be discriminated and the medicines that they use should be put on the positive list. This is demanded by the representatives of the associations "Give us wings" and "Life with Challenges".According to them, the prices of the medicines used by patients with rare diseases are very often unbearable for the family budget link to source
Press 24 Patients with rare diseases - not enough medicines	Not enough medicines for patients with rare diseases, treatments are late for months because of tender procedures, and each delay of treatment is a threat to their lives. link to source
Fokus MK Patients with rare diseases do not have enough medicines, treatments are late because of tender procedures	Not enough medicines for patients with rare diseases, treatments are late for months because of tender procedures, and each delay of treatment is a dangerous threat to their lives - complained the associations of people with rare diseases link to source
PlusInfo Associations for rare diseases demand that medicines are procured for the patients	Medicines which are urgently needed by some patients with rare diseases in order to live should be procured, to continue their introduction on the positive list and the suggestions for the programme for rare diseases to be put in a law, demand the associations for rare diseases and the National Alliance for rare diseases link to source
A1 On Conference for rare diseases organized by MASA	The Macedonian Academy of Sciences and Arts (MASA) organized the sixth conference for rare diseases, supported by the Macedonian association of medical doctors and the Macedonian Medical Chamber.

	link to source
Akademik MK Conference for rare diseases: The procurement of medicines for the treatment of rare diseases should be a priority	The associations for rare diseases and the National Alliance for rare diseases of Republic of Macedonia have demanded from the responsible institutions the proposals for the Programme for rare diseases to be put in a legislative framework, i.e this topic to be legally regulated. link to source
Lokalno MK CONFERENCE FOR SYSTEMATIC SOLUTIONS FOR RARE DISEASES	The first EUOPLAN Conference in Macedonia on the topic "Systematic solutions for rare diseases" will take place today in Skopje link to source
Republika EUROPLAN: A Centre for rare diseases is necessary, even a virtual one	It is necessary to define the notion of rare disease with which these patients will become visible and recognized as a separate category of people for whom special therapy and treatment is needed link to source
Meta MK Conference for rare diseases in MASA	The Macedonian Academy of Sciences and Arts organized today the sixth conference for rare diseases. The conference is aimed at pediatricians, internists, neurologists, nephrologists, doctors of family medicine, geneticists, biochemists, biologists, medical doctors from Macedonia and South-East Europe link to source
SakamDaKazam 70 PERCENT OF PATIENTS WITH RARE DISEASES ARE CHILDREN, THE PATIENTS DEMAND THAT THE STATE PROVIDE MEDICINES	Without therapy are about 40 percent of the registered patients with rare diseases in the country, according to the statistical data from the Ministry of Health. Until 1st January of this year in the registry run by the Ministry 347 patients have been registered with 46 diagnosis of rare diseases, of which 68 are children, that is to say under 16 years of age. link to source
MRT Patients with rare diseases four months without treatment	Regulative for rare diseases and for expensive medicines is demanded by patients and associations. They have complained about the lack of many medicines, but also about the high prices. There is not a law from the field of medicine where the term rare disease is mentioned, claim from the assocations... link to source
Samo Zdravje A CENTRE FOR RARE DISEASES IS NEEDED, AND PATIENTS SHOULD NOT BE INVISIBLE!	People suffering from a rare disease in Macedonia live in extremely difficult conditions, invisible to the law. It is necessary to define the notion of rare disease with what these patents will become visible and recognized as a special category of people for whom special treatment and therapy is needed,as well as defining the appropriate procedure for a timely procurement of medicines, a centre for rare diseases even a virtual one. link to source

Alfa No medicines for rare diseases, the patients - angry	The empty minister chair has enraged the patients with rare disease. They say that they need continuous need of treatment that should not depend of the political events and staff changes. link to source
Kanal 5 Conference for rare diseases in MASA	The number of rare diseases is huge and they represent 3-5% of each population. According to professor Guchev what is necessary is continuous... link to source
Mreza MK In MASA big scientific conference for rare diseases	In MASA big scientific conference for rare diseases link to source
MKD Conference for rare diseases in MASA	The Maccedonian Academy of Sciences and Arts orgnized today the sixth conference for rare diseases. The conference is aimed at pediatritians, internists, neurologists, nefrologists, doctors of family medicine, geneticists, biochemists, biologists, medical doctors from Macedonia and South-East Europe link to source
MakedonskiMediaServis (Macedonian Media Service) In MASA big scientific conference for rare diseases	In MASA big scientific conference for rare diseases link to source
24 Vesti Patients with rare diseases asking for better care by the state	Discontinuity in the treatment due to tender procedures and lack of new drugs are the greatest problems for the patients with rare diseases. link to source

ANNEX V – **PHOTOS**