

EUROPLAN National Conference
Poland
Kraków (Cracow), 22.10.2010

CONFERENCE FINAL REPORT

I. General information

Country	Poland
Date & place of the National Conference	22.10.2010 / October 22 nd 2010; Kraków (Cracow); Collegium Medicum, Jagiellonian University; ul. św. Anny 12, 31-008 Kraków
Website	http://www.europlan-rd.pl http://www.europlan.org.pl/
Organiser	Polish Cystic Fibrosis Foundation MATIO
Members of the Steering Committee	<u>Prof. Wojciech Cichy, MD, PhD</u> Head of the Department of Pediatric Gastroenterology and Metabolic Diseases, Poznan University of Medical Sciences <u>Prof. Tomasz Grodzicki, MD, PhD</u> Dean, Collegium Medicum, Jagiellonian University, Cracow <u>Mirosław Zieliński</u> Polish National Forum on the Treatment of Orphan Diseases – ORPHAN <u>Marcin Mikoś, MD</u> Poznan University of Medical Sciences <u>Paweł Wójtowicz</u> Chairman, Polish Cystic Fibrosis Foundation MATIO
Names and list of Workshops	<u>Panel I:</u> Methodology, Governance, Monitoring and Sustainability of a National Plan <u>Panel II:</u> Adequate Definition, Codification and

	<p>Inventorying of Rare Diseases including Information and Training</p> <p><u>Panel III: Clinical and Basic Research In Rare Diseases</u></p> <p><u>Panel IV: Standards of Care, Centers of Expertise and Orphan Drugs</u></p> <p><u>Panel V: Patient Empowerment and Gathering Expertise at the EU Level</u></p>
<p>Chairs and Rapporteurs of Workshops</p>	<p><u>Panel I: Methodology, Governance, Monitoring and Sustainability of a National Plan</u></p> <p>Chair – Mirosław Zieliński</p> <p>Polish National Forum on the Treatment of Orphan Diseases – ORPHAN</p> <p>Rapporteur – Marcin Mikoś, MD</p> <p>Poznan University of Medical Sciences</p> <p><u>Panel II: Adequate Definition, Codification and Inventorying of Rare Diseases including Information and Training</u></p> <p>Chair: Prof. Jolanta Sykut-Cegielska, MD, PhD, Department of Metabolic Diseases, Endocrinology and Diabetology, Children's Memorial Health Institute in Warsaw; Orphanet Poland clinical services national coordinator</p> <p>Rapporteur – Marcin Mikoś, MD</p> <p>Poznan University of Medical Sciences</p> <p><u>Panel III: Clinical and Basic Research In Rare Diseases</u></p> <p>Chair: Prof. Anna Tylki-Szymańska, MD, PhD, Professor of Paediatrics at the Children's Memorial Health Institute in Warsaw; Department of Metabolic Diseases; Professor of Medical Biology and Genetics</p> <p>Cardinal Stefan Wyszyński University</p> <p>Rapporteur: Marcin Mleczeko,</p> <p>Polish Cystic Fibrosis Foundation MATIO</p> <p><u>Panel IV: Standards of Care, Centers of Expertise and Orphan Drugs</u></p> <p>Chair: Jacek Galiński, MD,</p> <p>Vice-Director for Clinical Affairs; the Children's Memorial Health Institute in Warsaw</p>

	<p>Rapporteur: Marcin Mikoś, MD Poznan University of Medical Sciences <u>Panel V: Patient Empowerment and Gathering Expertise at the EU Level</u> Chair: Paweł Wójtowicz, Chairman, Polish Cystic Fibrosis Foundation MATIO Rapporteur: Marcin Mleczeko, Polish Cystic Fibrosis Foundation MATIO</p>
<p>Attachments</p>	<p>Attachment 1 – Evaluation of the situation in Poland in the field of Rare Diseases based on EUROPLAN Indicators Attachment 2 – Plan of the conference Attachment 3 – Letter from the Ministry of Health (in Polish and English) Attachment 4 – List of participants</p>

II. Main Report

Conference opening

Prof. Wojciech Cichy, MD, PhD opened the conference and welcomed participants.

A letter from the Ministry of Health, signed by Mr. Marek Twardowski, Undersecretary of the State was read (Attachement 4). The Ministry of Health supported the conference and underlined positive effects of cooperation on European level in the field of rare diseases and that the conference outcome will be a valuable input to further work for RDs in Poland.

Christel Nourissier, Secretary General EURORDIS and Supervisor of the Polish National EUROPLAN conference presented the EUROPLAN project.

Marcin Mikoś presented the content outline and plan of the conference (Attachment 2).

Discussions took place in five Panels.

92 participants took part in the conference (details in the Attachment 4).

Evaluation of the situation in Poland in the field of Rare Diseases based on EUROPLAN Indicators was conducted, the results are presented in Attachment 1.

Main and Horizontal Themes

Theme 1 and 6 - Methodology and Governance of a National Plan / Strategy (NP) and Sustainability

Addressed in Panel I: Methodology, Governance, Monitoring and Sustainability of a National Plan

Sub-Themes

1. Mapping exercise before developing a National Plan

Currently, no national plan or strategy for RDs exist in Poland. In 2008 the Ministry of Health (Directive of 21 July 2008) appointed the Rare Diseases Task Force – an advisory body to the Minister of Health. Although the creation of this body was generally very well accepted by RD stakeholders in Poland many unsolved issues remain. The task list of the Task Force list many activities (complete description in English in Aymé S., Rodwell C., eds., “2009 Report on Initiatives and Incentives in the Field of Rare Diseases of the European Union Committee of Experts on Rare Diseases”, July 2010), however, a point was made that it may only issue recommendations, lacks strategic tools for their implementation and most importantly for allocation of funds for RDs. Moreover, the meetings of the Task Force (held quarterly according to the document from 2008, in reality less often) are not frequent and regular enough. The Task Force lacks external evaluation.

Currently, since there is no integrated RD policy or plan / strategy, issues related to RDs are addressed by many scattered programs and policies. For instance, screening for phenylketonuria, cystic fibrosis, congenital deafness is done via the National Screening Program, additional 21 metabolic disorders are diagnosed by GC-MS in some regions (a pilot program financed by the Ministry of Health). Some of the drugs, including ODDs are reimbursed through the list of chronic disorders, another 5 ODDs are available through dedicated therapeutic programs of National Health Fund (“programy terapeutyczne NFZ”); diagnosis and treatment of rare cancers is financed by the National Program to Combat Cancers. Working group dedicated to ultrarare diseases was created at the National Health Fund (by the decision of the Ministry of Health).

Another important document in field of RDs in Poland was issued by the Polish Academy of Sciences, a Committee on Human Development (“Komitet Rozwoju Człowieka PAN”) – it is a statement regarding patient care in RDs from October 2009. This document contains following section regarding national plan for RDs: *“Ultimately, it seems reasonable to create a National Plan for Rare Diseases and establish separate Steering Committee, like other European countries (in transition, a Council affiliated to the Polish Academy of Sciences with representatives from all committees of the current term of office could serve this function)”*.

Moreover, during a meeting of representatives working for people affected by rare diseases in Poland held at the 5th European Conference for Rare Diseases in Kraków, Poland a following statement of physicians, healthcare professionals, scientists and members of RD patients’ organizations was accepted:

“In accordance with the concept of the 5th European Conference on Rare Diseases, bearing in mind the welfare of people with rare diseases in Poland, the recommendations of the European Commission and the opinion of the Committee on Human Development of Polish Academy of Sciences, in order to attain conformity of the Polish Health Care System with EU recommendations, the Polish participants of the meeting request to the Minister of Health, as the person responsible, the creation and implementation of the National Plan for Rare Diseases.

Participants of the meeting give full support to the Panel on Rare Diseases appointed by the Minister in its activities, particularly with regard to the feasibility of the realization tasks in accordance with the recommendations of the European Union. All these activities should result in the creation of the National Plan for Rare Diseases in the shortest possible timeframe. It would be advisable to rely on the guidelines of EUROPLAN as European platform to achieve the above objective.”

Unfortunately, the National Health Program 2007-2015 (“Narodowy Program Zdrowia 2007-2015”) does not mention RDs in any way.

During the discussion a point was made that the teams and working framework of National Consultants to the Minister of Health in all fields of medicine could be used to address medical issues in RDs, since the system is well coordinated and effective. However, integrated approach to RDs requires cannot be broken down to only medical field.

No special social services are available to RD patients and families, a tremendous amount of work is being done in this field by patients’ organizations and other NGOs.

2. Development and structure of a National Plan / Strategy

Experiences from above-listed frameworks and task forces / working groups should be used. EUROPLAN recommendations should be followed in the process.

3. Governance of a National Plan

Currently, since no national plan exists, the Rare Diseases Task Force acts as an advisory body to the Ministry of Health. The representation of all stakeholders in the Task Force is proportional, but could be improved before a plan is written (government, healthcare professionals and academia, pharmaceutical industry – Association of Producers of Medications, no orphan drugs producers, patients – wider representation recommended, but a single RD umbrella organization does not exist in Poland).

The institutions responsible for implementing the program should include Ministry of Health, Ministry of Science and Higher Education, Ministry of Social Policy, Ministry of National Education, Parliamentary Committee on Health

4. Monitoring the National Plan

EUROPLAN indicators recommended, an assessment of the situation before the plan is designed was conducted during the conference.

5. Sustainability of the National Plan

Through long-term financing in the state budget. Adequate evaluation of expenses for RDs might be difficult since diagnosis / treatment / medications / social care financed from a multitude of sources within the budget.

Themes 2 and 2.1 - Definition, codification and inventorying of RD / Information and training

Addressed in Panel II: Adequate Definition, Codification and Inventorying of Rare Diseases including Information and Training

Sub-Themes

1. Definition of RD

EU definition (5:1000 i.e. 1:2000, prevalence) officially not adopted. No RD definition is stated in the Directive of MoH of 21 July 2008 on the appointment of the Rare Diseases Task Force. National Health Fund therapeutic programs (“programy terapeutyczne NFZ”) use the name of ultra-rare disease (enzyme replacement therapies in ultra-rare diseased, mostly MPS’). RDs not mentioned in National Health Program 2007-2015 and Strategy for Development of Science in Poland to 2015.

2. Classification and traceability of RDs in the national health system

ICD-10 is widely used in the medical field (diagnosis) and ICD-9CM for medical procedures. SNOMED, OMIM, ORPHAN and SSIEM/IEM are also sometimes used. JGP (“Jednorodne Grupy Pacjentów”) is a system used by the National Health Fund (NFZ, Narodowy Fundusz Zdrowia) for registration and reimbursement of treatment and medical procedures. Traceability is insufficient in the healthcare system, as mentioned above, care in RDs is financed / reimbursed from many sources (hospital / outpatient / drugs from therapeutic programs and chronic diseases list / social care and services / patients’ organizations and NGOs). Physicians face problems in classifying treatment and procedures in JGP system of National Health Fund, special procedures in RDs often not listed at all, this constitutes big difficulty in hospital and outpatient treatment of RDs. All of this accounts to the fact that information is either totally lost or misleading, which causes inadequate representation of the epidemiologic situation (underestimation of the problem of RDs). This was particularly well demonstrated after the introduction of the screening program for cystic fibrosis – based on the calculated incidence number of people affected by CF should be much greater than known to date (possibly due to lack of established diagnosis, misdiagnosis, early deaths due to untreated complications).

3. Inventories, registries and lists

Many registries exist, some are very well constructed and have good coverage, for instance National Registry of Pediatric Cancers by the National Consultant, Polish Registry of Congenital Malformations (the latter may also include RDs in future). Active participation in many European registries: EUROCAT, EUROWILSON, EUROGLYCAN. Many other also exist, often lead by patients' organizations (CF, PKU, MPS) and orphan drugs producers. Overall registries often have limited coverage and no formal supervision (protection of personal data). The aim of creating registries shall be clearly defined to include not only informational and statistical purposes, but also enable treatment monitoring and disease progression by physicians (with adequate protection of vulnerable data). Centralised registries with appropriate coverage, supervision and data protection need to be developed.

2.1. Information and training

4. How to improve information on available care for RDs in general, for different audiences

For healthcare professionals / social workers: training sessions, conferences, exchange of information.

General public: RD events, Rare Disease Day, media, Internet. Especially for mass-media, press and Internet use of validated and trustworthy information (verified by professionals) is important to avoid disinformation.

Patients and families: organizations / networking / NGOs

5. How to improve access to quality information on RDs

Webpages of Centres of Reference on RDs, umbrella organizations (in cooperation with professional, validated information)

6. How to ensure adequate training of healthcare professionals on RDs

Undergraduate: inclusion of RD-specific training in the official curriculum (medicine / public health / social sciences). RD facultative classes for particularly interested students. Cooperation of students' organizations (motivated, active) with patients' organizations / NGOs. At the moment extent of RD-related differs greatly between universities.

Postgraduate: Updating the programs of specialisation to cover RDs (paediatrics, genetics, neurology, oncology). Multi-centre training and research projects. RD-specialisation in future?

Theme 3 - Research on RD

Addressed in Panel III: Clinical and Basic Research In Rare Diseases

Sub-Themes

1. Mapping of existing research resources, infrastructures and programmes for RDs'

Only in a few centres, mostly basic research, some clinical application / trials. Participation in the EU projects is insufficient. No dedicated research programs for RDs, they are financed within general application process for state-funded research. No recruitment of scientists specifically for RDs.

2. Needs and priorities for research in the field of RDs

Wider EU-cooperation, funding RD post-doc programs for young researchers. Incentives and programs for graduates to pursue a career in Poland. Promoting mobility (scholarships, international projects) and balancing “brain drainage” on the other hand – after having completed an international project researchers should have a post to return to. Positive example of FNP (Polish Science Foundation) – projects TEAM / RETURN – however they are addressed for all fields of science. No such programs exist in the field of RDs.

3. Fostering interest and participation of national laboratories and researchers, patients and patient organisations in RD research projects

Currently it depends on personal area of interest of the researchers / laboratories. Involvement of patients and patient organizations is more frequent, often coordinated at the level of centre of expertise, sometimes as an initiative of patient organization.

4. Sustainability of research on RD

Long-term funding, EU project participation, diversified funding sources (not relying only on state-funded research which often is a case in Poland) and international cooperation seem to be of greatest value.

5. EU collaboration on research on RD

Is undoubtedly a priority, insufficient at the moment: according to Aymé S., Rodwell C., eds., “2009 Report on Initiatives and Incentives in the Field of Rare Diseases of the European Union Committee of Experts on Rare Diseases”, July 2010 – participation in EU projects: DG SANCO - 8 participating, E-RARE - 0 (NCBiR has observer status), FP5 - 1 participating, FP6 - 7 participating, FP7 - 3 participating, no projects coordinated.

Themes 4 and 4.1 - Standards of care for RDs - Centres of Expertise (CoE)/ European Reference Networks (ERN) and Orphan Drugs (OD)

Addressed in Panel IV: Standards of Care, Centres of Expertise and Orphan Drugs

Sub-Themes

1. Identification of national or regional CoE all through the national territory by 2013

No official policy in this field exist. On a national level probably around 10-15 centres exist. They are “nominated” by reputation and experience in a given field, each of them conducts diagnostics and

treatment to different extent. According to Aymé S., Rodwell C., eds., “2009 Report on Initiatives and Incentives in the Field of Rare Diseases of the European Union Committee of Experts on Rare Diseases”, July 2010 *“In Poland, the health care of patients with rare diseases is not organised in a specific framework and there are no official centres of expertise for rare diseases. Significant progress has been made as a result of the European Project of Centres of Excellence “PERFECT” QLG1-CT-2002-90358. The grant programme included problems associated with rare paediatric diseases in the field of genetics, metabolism, gastroenterology, cardiology, immunology and oncology.”* This information is up-to-date as of 2011 as well. Creation of, constant updating, transparent publication and sharing the list of centres of expertise will be necessary. In the discussion it was also underlined that CoEs should conduct professional, high quality laboratory and genetic diagnostics with external evaluation, since incompetence and mistake in this field question the trustworthiness of healthcare system.

2. Sustainability of CoE

Continuous training of medical professionals in CoEs, adequate resources and funding. Officially designating CoEs in case of Poland will be the first step in ensuring sustainability.

3. Participation in ERN

Only a few centres participate in European reference networks so far, much broader participation will be required when CoEs are officially designated.

4. How to shorten the route to diagnosis and offer suitable care and organise adequate healthcare pathways for RD patients

An improvement in the field of RDs calls for thorough optimization of the healthcare system, from legislation to effective implementation. Moreover, enabling diagnosis at the earliest possible moment, ultimately prenatal and neonatal screening and defining detailed actions to undertake in case of positive screening or diagnostic test result are necessary. Patients need support in complicated healthcare system, which in case of Poland is deeply divided into primary / GP care and specialist care. Coordinated care approach in case of RDs (CoE physician acting as a coordinator) greatly optimizes the treatment process and increases its cost-effectiveness.

5. How to ensure in CoE multidisciplinary approaches and integration between medical and social levels

In the field of rare diseases in particular separating medical and social care has no justification, since patients’ problems do not disappear after being discharged from hospital. Social care and rehabilitation shall be integrated with medical care, for instance a social worker and psychologist may discuss current issues with patient and family during a visit in the centre of expertise.

6. How to evaluate CoE

Currently no evaluation scheme is being used. Designation of CoE should include evaluation program including the voice of patients.

4.1. Orphan Drugs (OD)

7. Future of OD

Minimizing registration delay, clear rules of qualification to treatment and reimbursement.

8. Access of RD patients to orphan drugs Pricing and Reimbursement

Some of the drugs, including ODDs are reimbursed through the list of chronic disorders, another 5 ODDs are available through dedicated therapeutic programs of National Health Fund (“programy terapeutyczne NFZ”).

9. Compassionate use and temporary approval of orphan drugs. Off label use.

No official Compassionate Use policy. Compassionate use is a subject to individual decision of the Minister of Health. Even if the company would donate a drug it is a subject to taxation, which further potentially limits compassionate use. Off-label use is a decision of physician according to regulations of “treatment experiment” after unsuccessful application of standard treatment methods.

Themes 5 and 7 - Patient Empowerment and Specialised Services and Gathering expertise at the EU level

Addressed in Panel V: Patient Empowerment and Gathering Expertise at the EU Level

Sub-Themes

1. Involvement of patients and their representatives in decision-making processes in the field of RDs

Currently two patients’ organization representatives are members of Rare Diseases Task Force (one – patients in general and one – RD patients). Once national plan is designed this number should increase to ensure wider representation along with a representative of an RD umbrella organization (which does not exist at the moment).

2. Support to the activities performed by patient organisation

Practically none - they are financed from private organizations’ funds (mostly fundraising and “1% tax initiative” – tax payers may transfer one percent of the tax paid to an organization from the official list).

3. Specialised social services: Respite Care Services; Therapeutic Recreational Programmes; Services aimed at the integration of patients in daily life

Respite care *per se* in RDs does not exist. Therapeutic and recreational services such as camps are eligible for co-funding by the state social care (usually with 30% patient co-payment). Services aimed at the integration of patients in daily life are eligible only for people with disabilities, general rules apply. The state finances the integration of children with special needs, via integration classes in schools. Programs specifically for RD patients available only through patients' organizations.

4. Help Lines

No dedicated national RD Help Lines exist. Information disseminated mostly by patients' organizations. People may also call reference centres

Conclusion of the Final Report

Currently no plan or strategy exists in Poland, but substantial steps were undertaken in the field of RDs in the last years. At this point the EUROPLAN tools are particularly useful to evaluate the situation before creating an integrated strategy. Recommendations and indicators which assume existence of a plan or strategy as well as centres of reference are less applicable in this case. Possibly diversifying them for EU member states either with or still without a plan or strategy might further increase their usefulness in members which are still a "step back" in this field.

In terms of transferability of the EUROPLAN Recommendations we believe they represent an optimal model that all EU member should strive for, although especially in the new member states their adoption might be particularly difficult due to less effective healthcare system and economic delay. The Ministry of Health of Poland in the official letter to the conference participants does not mention integrated plan or strategy in any way, stating instead that "[...] *the conference completely addresses all fields which need to be considered in order to find a complete solution of our common problem, which shall be also adapted to Polish conditions*" and mentions "*conducting feasible activities in this field*". Although every progress in this field is beneficial and accounts for improved quality of life, we believe that is the final moment to take more decisive actions in order to meet the 2013 deadline of implementing an integrated strategy for RDs.

III. Document history

Status (Draft/Reviewed/Final)	Draft
Version n°	3
Author(s)	Marcin Mikoś
Reviewer	Christel Nourissier
File name	EUROPLAN_Poland_report.doc

Attachment 1 – Evaluation of the situation in Poland in the field of Rare Diseases based on EUROPLAN Indicators

Area 1. - Global policy strategies on RD

Note: Total number of votes differ between indicators since entering /exiting the conference hall was not restricted

Number	Indicator	Answer	Votes	Comments
1.1	Existence of regulations / laws that support the creation and development of a RD plan	Not existing, not clearly stated	For: 25, Against: 1, Abstain: 3	Some regulations exist (in particular creation of an advisory body, the Rare Diseases Task Force at the MoH level), no national plan or strategy , RDs not mentioned in National Health Program 2007-2015
1.2	National/regional (percentage of regions)	0%	For: 26, Against: 1, Abstain: 0	No region with a plan implemented.
1.3	Existence of a coordination mechanism	Not existing, not clearly stated	For: 25, Against: 1, Abstain: 0	Since no plan or strategy is available, no coordination mechanisms exist. Some coordination-related tasks are responsibility of the Rare Diseases Task Force, however, it is only an advisory body to the MoH.
1.4	Existence of an expert advisory committee	Does not exist	For: 21, Against: 1, Abstain: 3	Some expert committees exist, for instance Human Development Committee, Polish Academy of Sciences (Komitet Rozwoju Człowieka PAN), which has issued a statement regarding patient care in RDs in October 2009. This document contains following section regarding national plan for RDs: “Ultimately, it seems reasonable to create a National Plan for Rare Diseases and establish separate Steering Committee, like other European countries (in transition, a Council affiliated to the Polish Academy of Sciences with representatives from all committees of the current term of office could serve this function)”. This is one possible solution for creating and expert advisory committee.
1.5	Existence of an external evaluation body/procedure	0 - none	For: 23, Against: 1, Abstain: 1	No external evaluation body or procedure exist. Such procedures should be created according to EUROPLAN recommendations.
1.6	Number of priority areas included in the plan	3 (1-10)	For: 21, Against: 0, Abstain: 1	Priority areas are not officially listed, since no plan / strategy was prepared so far. However during the discussion a point was made that some priority areas are listed in the Directive of MoH of 21 July 2008 on the appointment of the Rare Diseases Task Force. The evaluation of this indicator is based on priority areas of the Task Force.
1.7	Budget of plan/strategy	No exact figures known	For: 21, Against: 0, Abstain: 1	No integrated budget was prepared.

Area 2. - Adequate definition, codification and inventorying of rare diseases

Number	Indicator	Answer	Votes	Comments
2.1	Adoption of the EC RD definition	Not	For: 16, Against: 0, Abstain: 0	Definition officially not adopted. No RD definition in Directive of MoH of 21 July 2008 on the appointment of the Rare Diseases Task Force. One of the National Health Fund therapeutic programs (programy terapeutyczne NFZ) uses the name of ultra rare disease (enzyme replacement therapies in ultra-rare diseased, mostly MPS'). RDs not mentioned in National Health Program 2007-2015 and Strategy for Development of Science in Poland to 2015.
2.2	Type of classification used by the health care system	ICD-10, ICD-9CM, SSIEM by IEM, JGP, CPT4PL	For: 18, Against: 0, Abstain: 1	ICD-10 is widely used in the medical field (diagnosis) and ICD-9CM for medical procedures. JGP (Jednorodne Grupy Pacjentów) is a system used by the National Health Fund (NFZ, Narodowy Fundusz Zdrowia) for registration and reimbursement of treatment and medical procedures. CPT4PL is also sometimes used for statistical purposes.
2.3	Developing policies for recognizing RD by the care information systems	Not existing, not clearly stated	For: 19, Against: 0, Abstain: 0	Registration of the treatment of RDs is often difficult due to lack of procedures for reimbursement (JGP system). RDs are often "lost" in the healthcare information system. This problem is particularly visible in the reference centers.
2.4	Registering activity	Multiple RD registries, not standardized	For: 22, Against: 0, Abstain: 0	Many registries exist, some are very well constructed for instance National Registry of Pediatric Cancer, Polish Registry of Congenital Malformations. Active participation in many European registries: EUROCAT, EUROWILSON, EUROGLYCAN, TREAT-NMD, EUROCARE CF. Many other also exist, often lead by patients' organizations (CF, PKU) and orphan drugs producers. Overall registries often have limited coverage, are not well enough coordinated and have no formal supervision (protection of personal data).
2.5	Number of diseases included	No data available	For: 21, Against: 0, Abstain: 0	No trustworthy data available, multiple registries.

Area 3. - Research on Rare Diseases

Number	Indicator	Answer	Votes	Comments
3.1	Existing a RD National/Regional research programs	RD research program included in the general research program as a priority	For: 19, Against: 0, Abstain: 0	No dedicated research programs in RDs, they are financed within different programs (general application process for state-funded research)
3.2	RD research program monitoring	Not existing, not clearly stated	For: 22, Against: 0, Abstain: 0	Standard monitoring applies like for other state-funded research projects
3.3	Number of RD research projects approved by year (if possible yearly starting the year before plan commencement)	About 10%	For: 19, Against: 0, Abstain: 0	About 10% projects approved for funding is related with RDs
3.4	Clinical trials funded by public bodies	Yes, action implemented	For: 31, Against: 0, Abstain: 0	Funding source underestimated in Poland
3.5	E-RARE joining	In process	For: 32, Against: 0, Abstain: 0	Observer – new funding organization NCBiR
3.6	Including public health and social research, in the field of rare diseases	Under discussion	For: 31, Against: 0, Abstain: 0	
3.7	Research platforms and other infrastructures are also funded by the research program	No	For: 31, Against: 0, Abstain: 0	
3.8	Number of young scientists recruited every year to work specifically on rare diseases	0	For: 32, Against: 0, Abstain: 0	No specific recruitment for RDs. General application rules in research institutes, scientists may work with different projects
3.9	There are specific public funds allocated for RD research	No	For: 33, Against: 0, Abstain: 0	No specifically allocated funds for RDs. General application rules apply for state-funded research.
3.10	Funds specifically allocated for RD research actions/projects per year since the plan started	No data available/ 0%	For: 33, Against: 0, Abstain: 0	No specifically allocated funds for RDs. General application rules apply for state-funded research.

Area 4. - Centres of Expertise

Number	Indicator	Answer	Votes	Comments
4.1	Existence of a policy for establishing centers of expertise at the national/regional level	Not existing, not clearly stated	For: 19, Against: 0, Abstain: 0	Usually centers of 3 rd degree of reference (clinical, teaching hospitals). No official policy.
4.2	Number of centres of expertise adhering to the policy defined in the country	No data - since no definition / policy	For: 19, Against: 0, Abstain: 0	No official definition and policy – number difficult to evaluate. On a national level probably around 10-15 centres exist. They are “nominated” by reputation and experience in a given field, each of them conducts diagnostics and treatment to different extent.
4.3	Groups of rare diseases followed up in centres of expertise	Covering only some rare diseases	For: 19, Against: 0, Abstain: 0	National coordinating centre for metabolic rare diseases: Children’s Memorial Health Institute in Warsaw, regional centers offer diagnostics and treatment often in cooperation with Children’s Memorial HI Warsaw.
4.4	Centres of expertise adhering to the standards defined by the Council Recommendations - paragraph d) of preamble	Only a few	For: 20, Against: 0, Abstain: 0	
4.5	Participation of national or regional centres of expertise into European reference networks	Only a few	For: 23, Against: 0, Abstain: 0	

Area 5. - Empowerment of patients

Number	Indicator	Answer	Votes	Comments
5.1	Number of umbrella organisations specific on rare diseases	Existing, more than one organization	For: 22, Against: 0, Abstain: 0	A few organizations exist, one gathering all organizations – does not exist
5.2	Having a directory of RD patients' organizations	Yes	For: 22, Against: 0, Abstain: 0	Few such lists exist, specific not only to RDs
5.3	Number of Patients' associations	20-40	For: 22, Against: 0, Abstain: 0	Including inactive organizations, lost contact etc.
5.4	Number of diseases covered by patients' associations	Over 1000	For: 22, Against: 0, Abstain: 0	
5.5	Permanent and official patients' representatives in plan development, monitoring and assessment	Considered in the plan, not effectively implemented	For: 22, Against: 0, Abstain: 0	
5.6	Participation of patients organizations in the development of RD research strategies	Yes	For: 22, Against: 0, Abstain: 0	In some cases, very rarely
5.7	Participation of patients organizations in the RD centres of expertise designation and evaluation	No	For: 22, Against: 0, Abstain: 0	
5.8	Resource (funding) provided for supporting the activities performed by patient organizations	0	For: 22, Against: 0, Abstain: 0	No plan or strategy
5.9	Support to sustainable activities to empower patients, such as awareness raising, capacity-building and training, exchange of information and best practices, networking, outreach to very isolated patients	0	For: 22, Against: 0, Abstain: 0	No activities within the plan, since it was not prepared. Patients' organizations are very active in this field
5.10	Availability of Help line for RD	Referred RD help lines	For: 22, Against: 0, Abstain: 0	Run by patient's organizations

Area 6. - Sustainability of rare diseases activities

Number	Indicator	Answer	Votes	Comments
6.1	Existing policy/decision to ensure long-term sustainability of the RD plan /strategy (the field of 1. information, 2. research and 3. healthcare for rare diseases)	Not (don't exist)	In the field of - Information: For: 27, Against: 0, Abstain: 1 Research: For: 24, Against: 6, Abstain: 3 Healthcare: For: 24, Against: 0, Abstain: 2	In the discussion it was decided to split the answer into 3 fields: information, research and healthcare
6.2	Amount of funds allocated for ensuring RD plan /strategy sustainability	30 millions of Euros (treatment of ultra-rare diseases and cystic fibrosis, calculated from national budget 2010); no other data available	For: 23, Against: 0, Abstain: 6	Funds allocated for treatment of ultra-rare diseases (treatment programs – orphan drugs – enzymes) and cystic fibrosis (screening and treatment). Apart from that no data available.
6.3	Existing policy/decision to ensure the contribution to support RD European infrastructures	Not existing, not clearly stated	For: 27, Against: 0, Abstain: 0	No policy in this field.

Area 7. - Access to Orphan Designated Drugs (ODD)

Number	Indicator	Answer	Votes	Comments
7.1	Number of ODD market authorizations by EMEA and placed in the market in the country	Available – all of 62, reimbursed – about a half, no exact data	For: 14, Against: 0, Abstain: 0	No exact data known even to representatives of Federation of Orphan Drugs Producers in Poland present during the session. 5 of the ODDs are available through dedicated therapeutic programs of National Health Fund (programy terapeutyczne NFZ). Some ODDs are reimbursed through list of chronic disorders.
7.2	Time between the date of a ODD market authorization by EMEA and its actual date of placement in the market for the country	No exact data available	For: 11, Against: 0, Abstain: 0	No exact data known even to representatives of Federation of Orphan Drugs Producers in Poland present during the session.
7.3	Time from the placement in the market in the country to the positive decision for reimbursement by public funds	No exact data available	For: 11, Against: 0, Abstain: 0	No exact data known even to representatives of Federation of Orphan Drugs Producers in Poland present during the session.
7.4	Number of ODD reimbursed 100%	More than 10% of available	For: 14, Against: 0, Abstain: 1	No exact data available.
7.5	Existence of a governmental program for compassionate use for Rare Diseases	Yes, individual decision of the MoH	For: 11, Against: 0, Abstain: 0	No official Compassionate Use policy. Treatment is a subject to individual decision of the Minister of Health. Even if the company would donate a drug it is a subject to taxation, which further potentially limits compassionate use. Better policy should be developed.

Area 8. – Diagnosis

Number	Indicator	Answer	Votes	Comments
8.1	Number of diseases included in the neonatal screening program	4 nationwide: 3 (laboratory) + 1 congenital deafness. Additional 21 in some regions	For: 20, Against: 0, Abstain: 1	3 included in national screening program: hypothyroidism, phenylketonuria, cystic fibrosis (since 2006). Apart from laboratory tests there is also screening program for congenital deafness conducted in neonatology departments. Additional 21 metabolic disorders diagnosed by GC-MS available in some regions through a pilot program financed by the MoH. departments.
8.2	Number of diseases included in the neonatal screening program properly assessed	4/4=100%	For: 20, Against: 0, Abstain: 1	All screening programs have appropriate assessment
8.3	Existence of a public directory/ies of both genetic tests on Rare Diseases	Yes, Orphanet database	For: 20, Against: 0, Abstain: 1	Very important aspect, quality of tests and follow-up counseling is of tremendous importance
8.4	Proportion laboratories having at least one diagnostic test validated by an external quality control	No data available	For: 20, Against: 0, Abstain: 10	Most laboratories have external quality control, no exact numbers known. Institute of Mother and Child, Warsaw is responsible for nationwide neonatal screening.

Area 9. - Specialized social services

Number	Indicator	Answer	Votes	Comments
9.1	Existence of official programs supporting patients and families with disabilities	Not existing, not clearly stated	For: 15, Against: 0, Abstain: 0	Specific programs available only through organizations. Official programs aimed at disabled people only, rare disease patients are eligible if they are qualified as disabled, i.e. disability is not assumed for all patients with rare diseases
9.2	Existence of an official directory of social resources for patients with disabilities	No	For: 15, Against: 0, Abstain: 0	No such directory is available, lists of potential resources run by patients' organizations
9.3	Existence of national schemes promoting access of RD patients and their families to Respite Care services	No	For: 15, Against: 0, Abstain: 0	Respite care services are not known at all in Poland.
9.4	Existence of public schemes supporting Therapeutic Recreational Programs	Yes	For: 15, Against: 0, Abstain: 0	Only for people with disabilities, general rules apply. Not for RD patients if they are not qualified as disabled. Programs specifically for RD patients available only through patients' organizations.
9.5	Existence of programs to support integration of RD patients in their daily life	No	For: 15, Against: 0, Abstain: 0	Only for people with disabilities, general rules apply. Not for RD patients if they are not qualified as disabled. Programs specifically for RD patients available only through patients' organizations.
9.6	Existence of programs to support rehabilitation of RD patients	No	For: 15, Against: 0, Abstain: 0	Only available through patients' organizations

Area 10. - Promotion of health knowledge and expertise

Number	Indicator	Answer	Votes	Comments
10.1	Existence of a comprehensive national and/or regional RD information system supported by the government	No formal decisions have been taken	For: 15, Against: 0, Abstain: 0	Information disseminated mostly by patients' organizations / NGOs
10.2	Help lines for professionals	No formal decisions have been taken	For: 15, Against: 0, Abstain: 0	No help lines, only personal contacts of professionals
10.3	Help lines for patients	In process	For: 15, Against: 0, Abstain: 0	In most cases run by patients' organizations / NGOs
10.4	Clinical guidelines	30	For: 15, Against: 0, Abstain: 0	
10.5	Number of such as activities promoted by the plan/strategy	0 within plan / strategy	For: 15, Against: 0, Abstain: 0	Many activities of patients' organizations / NGOs: raising awareness, training sessions for physicians, physiotherapists, nurses, facultative classes for medical students, Rare Disease Day etc.

Polish EUROPLAN Project Conference

Kraków, 22.10.2010



EURORDIS
Rare Diseases Europe

Uniwersytet Jagielloński, Collegium Medicum

ul. św. Anny 12, 31-008 Kraków

Steering Committee:

Prof. Wojciech Cichy, MD, PhD, Prof. Tomasz Grodzicki, MD, PhD

Mirosław Zieliński, Marcin Mikoś, MD, Paweł Wójtowicz

Plan

10:00 - 10:30	Opening of the conference
10:30 – 11:00	Plenary I EUROPLAN Project - introduction
11:00 - 12:30	Panel I: Methodology, Governance, Monitoring and Sustainability of a National Plan <i>Chair: Mirosław Zieliński</i>
12:30 – 13:00	Coffee break
13:00 - 14:30	(two conference halls, parallel sessions) Panel II: Adequate Definition, Codification and Inventorying of Rare Diseases including Information and Training <i>Chair: Prof. Jolanta Sykut-Cegielska, MD, PhD</i> Panel III: Clinical and Basic Research In Rare Diseases <i>Chair: Prof. Anna Tylki-Szymańska, MD, PhD</i>
14:30 - 15:30	Lunch break
15:30 – 17:00	(two conference halls, parallel sessions) Panel IV: Standards of Care, Centers of Expertise and Orphan Drugs <i>Chair: dr Jacek Graliński, MD</i> Panel V: Patient Empowerment and Gathering Expertise at the EU Level <i>Chair: Paweł Wójtowicz</i>
17:00 - 18:00	Plenary II Conclusions from panel discussions Closing of the conference

Warsaw, October 20th 2010

Ministry of Health

Undersecretary of the State

Marek Twardowski

Participants of the

EUROPLAN Polish National Conference

I regret to announce that due to urgent professional duties I will not be able to participate in the conference organized within EUROPLAN project, which constitutes an important step in helping patients suffering from rare diseases.

Representatives of all EU member states, including Poland, participate in this project. The Ministry of Health appreciates the significance of this initiative which enables us to take advantage of experiences of other countries. The final recommendations play a substantial role in the project.

The Ministry of Health supports the initiative of raising awareness about rare diseases in a possibly broadest aspect, especially through National Conferences, which have been successful in other member states.

The plan of the conference completely addresses all fields which need to be considered in order to find a complete solution of our common problem, which shall be also adapted to Polish conditions.

The Ministry of Health continues the policy of the current government in the field of rare diseases. The European Conference of Rare Diseases has fulfilled its goals and contributed to another meeting of the Rare Diseases Task Force and conducting feasible activities in this field.

I also deeply believe that equally that the EUROPLAN National Conference will play an equally useful role thank to interesting and inspiring discussions.

Activities undertake at the European level in the field of rare diseases clearly show that cooperation of all stakeholders may bring good effects, especially in this difficult and specific field

It remains to wish you a very interesting and fruitful conference, which will help us all in acting better for the ones most important for us – the patients.

Sincerely,

(signature illegible)



MINISTERSTWO ZDROWIA
PODSEKRETARZ STANU
Marek Twardowski

Warszawa, dnia

Uczestnicy

Narodowej Konferencji EUROPLAN

Szanowne Państwo

Z przykrością przyszło mi poinformować, że pilne obowiązki służbowe uniemożliwiły mój udział w Konferencji organizowanej w ramach projektu EUROPLAN, który stanowi ważny etap na drodze do lepszej pomocy dla pacjentów cierpiących na choroby rzadkie.

W projekcie EUROPLAN uczestniczą przedstawiciele wszystkich państw członkowskich Unii Europejskiej, w tym Polski. Ministerstwo Zdrowia docenia wagę tej inicjatywy, gdyż pozwala ona nam na naukę w oparciu o doświadczenia innych państw. Szczególną rolę pełnią rekomendacje, których przygotowanie w ramach projektu zostało zakończone.

Tym bardziej Ministerstwo Zdrowia popiera inicjatywę jak najszerszego rozpowszechniania wiedzy w zakresie chorób rzadkich, zwłaszcza poprzez Narodowe Konferencje, które z sukcesem odbyły się już w innych krajach.

Bardzo cieszy plan Konferencji, który odzwierciedla tematyką poszczególne elementy, których uwzględnienie będzie konieczne dla znalezienia całościowego rozwiązania naszego wspólnego problemu, które jednocześnie będzie dopasowane do polskich realiów.

Ministerstwo Zdrowia kontynuuje politykę obecnego rządu w zakresie chorób rzadkich. Majowa Europejska Konferencja Chorób Rzadkich spełniła swoje zadanie i stała się przyczynkiem do kolejnego spotkania Zespołu do spraw Chorób Rzadkich i prowadzenia realnych działań w tym zakresie. Jednocześnie mam głęboką nadzieję, że równie użyteczna funkcja przypadnie Narodowej Konferencji EUROPLAN dzięki interesującym i inspirującym dyskusjom.

Działania podejmowane na poziomie wspólnotowym w zakresie chorób rzadkich, wyraźnie pokazują, jak dobre efekty może przynieść współpraca wszystkich zainteresowanych, zwłaszcza w tym trudnym i specyficznym obszarze.

Pozostaje mi życzyć Państwu niezwykle interesującej i owocnej Konferencji, która pomoże nam wszystkich lepiej działać na rzecz osób najważniejszych dla nas - pacjentów.

Z wyrazami szacunku,

M. Twardowski

**EUROPLAN National Conference
Poland
Kraków (Cracow), 22.10.2010**

**CONFERENCE FINAL REPORT
ATTACHMENT 4 – LIST OF PARTICIPANTS**

Total number of participants (signed the list): 92

NGOs / Patients' Organizations representatives: 37 (cystic fibrosis - MATIO, Fabry syndrome, Marfan syndrome, Williams syndrome, Gaucher disease, muscular dystrophies, multiple myeloma, mucopolysaccharidoses and ultra-rare diseases, pulmonary hypertension, phenylketonuria, congenital heart disease, rare diseases in general, disabilities, Polish Federation of Patients, Polish National Forum on the Treatment of Orphan Diseases – ORPHAN, EURORDIS)

MDs: 11 (paediatrics, gastroenterology, endocrinology, neurology, genetics, internal medicine, surgery)

Pharmaceutical companies: 4

Government: 1 (Local Voivodeship Office), letter from the Ministry of Health

News/Media: 5

Students: 35 (medicine, public health, pharmacy)

During workshops 11-32 participants were present (according to voting records on EUROPLAN indicators)

Following are the scanned lists of participants

WYDZIAŁ PRAWO I ADMINISTRACJA
 KATEDRA PRAWA I ADMINISTRACJI
 ul. 29 STYC. 101, 01-507 KRAKÓW, AL. GAIŁARZA 6
 tel. 26 25 51 00, fax 26 25 54 72

Ep	Imię i Nazwisko	Przebieg choroby	Przebieg choroby
1	Andrzej Szlachetka		
2	Anna Nieroda		
3	Anna Nieroda		
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19	Imię i Nazwisko	Imię i Nazwisko	Adres
20	RENATA NIEDZIŁKA	Stowarzyszenie Inżynierów i Techników Chemików (I.C.T.C.)	ul. S. C. K.
21	Krzysztof Knapik	Stowarzyszenie Inżynierów i Techników Chemików (I.C.T.C.)	ul. S. C. K.
22	Anna Mieloch	Stowarzyszenie Inżynierów i Techników Chemików (I.C.T.C.)	ul. S. C. K.
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45	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.
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59	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.
60	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.
61	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.
62	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.
63	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.
64	RENATA NIEDZIŁKA	PROBLEMY WOLONTARIATU PRACOWNIKÓW M. GARDNOVA	ul. S. C. K.

Lp.	Imię i Nazwisko	Uczelnia	Adres	Podpis
1	Paulina Paszoniak	CH UJ	ul. S. C. K.	Paulina Paszoniak
2	Barbara Kuciszewska	CH UJ	ul. S. C. K.	Barbara Kuciszewska
3	Laura Legutka	CH UJ	ul. S. C. K.	Laura Legutka
4	Magnolia Futura	CH UJ	ul. S. C. K.	Magnolia Futura
5	Mariusz Rogozik	CH UJ	ul. S. C. K.	Mariusz Rogozik
6	Ewa Siarota	CH UJ	ul. S. C. K.	Ewa Siarota
7	Barbara Sos	CH UJ	ul. S. C. K.	Barbara Sos

8	Agata Wawrzynińska	CH UJ	ul. S. C. K.	Agata Wawrzynińska
9	Ewelina Bityl	CH UJ	ul. S. C. K.	Ewelina Bityl
10	Emilia Sobala	CH UJ	ul. S. C. K.	Emilia Sobala
11	Julijana Socha	CH UJ	ul. S. C. K.	Julijana Socha
12	Olga Ant	CH UJ	ul. S. C. K.	Olga Ant
13	Krzysztof Chmielowiec	CH UJ	ul. S. C. K.	Krzysztof Chmielowiec
14	Justyna Pastuszka	CH UJ	ul. S. C. K.	Justyna Pastuszka
15	Dorota Kram	CH UJ	ul. S. C. K.	Dorota Kram
16	Joanna Zmarak	CH UJ	ul. S. C. K.	Joanna Zmarak
17	Magnolia Futura	CH UJ	ul. S. C. K.	Magnolia Futura

Studencki Uniwersytet
Klasa wul. 1/60

Wzrost: 170 cm
Ciężar ciała: 60 kg
Ciepłota ciała: 36,6°C
Ciężar serca: 230-250 g
Ciężar płuc: 1,2-1,5 kg
Ciężar wątroby: 1,5-2,0 kg
Ciężar nerek: 120-150 g

	Adres	Radca	Radca
18 Przemysław Świątek	CHUS	Krzysztof ul. Sucho 14 90-189 Kraków	Kozłowski
19 Agnieszka Kujal	CHUS	ul. 4 Maja 22/2 31-500 OPOLSKO	Kozłowski
20 Jolita Kozłowski	CHUS	ul. Żmigrodzka 26 16-124 Siedlce	Kozłowski
21 Karolina Kula	CHUS	ul. Brzozowa 60 31-555 Białystok	Babiarz
22 Beata Dorwin			
23 Beata Dymarska			
24 Dominika Michalczyńska			
25 Urszula Kozłowski	CHUS	ul. Orzechowa 5/11 31-085 Wrocław	Kozłowski
26 Karolina Kozłowski	CHUS	ul. Świdnicka 45/10 51-112 Wrocław	Kozłowski
27 Zuzanna Czernicka			Kozłowski

	Adres	Radca	Radca
28 Eliza Gbur	CHUS	ul. Świdnicka 45/10 51-112 Wrocław	Kozłowski
29 Eliza Zawadzka	CHUS	ul. PCK 30m 17 26-600 Białystok	Kozłowski
30 Dagmara Pieter			
31 Luiza Orzywek			
32 Ewelina Wołoska			
33 Katarzyna Lisicki		Klementyna 268 32-112 Klimontów	Kozłowski
34 Katarzyna Mazur		Sorego 15/7 31-047 Kraków	Kozłowski
35 Sylwia Szturpa		Skłodowska 57/44 K-06 06-100 Kozłowski	Kozłowski
36 Anna		57/39 Kursowa 37/2 Kozłowski	Kozłowski
37 Beata			Kozłowski

	Adres	Radca	Radca
38 Daria Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
39 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
40 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
41 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
42 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
43 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
44 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
45 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
46 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski
47 Tomasz Kozłowski		ul. 1 Maja 139 52-086 Wrocław	Kozłowski

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