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 22nd 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	Prof. Wojciech Cichy, MD, PhD Head of the Department od Pediatric Gastroenterology and Metabolic Diseases, Poznan University of Medical Sciences Prof. Tomasz Grodzicki, MD, PhD Dean, Collegium Medicum, Jagiellonian University, Cracow Mirosław Zieliński Polish National Forum on the Treatment of Orphan Diseases – ORPHAN Marcin Mikoś, MD Poznan University of Medical Sciences Paweł Wójtowicz Chairman, Polish Cystic Fibrosis Foundation MATIO
Names and list of Workshops	Panel I: Methodology, Governance, Monitoring and Sustainability of a National Plan Panel II: Adequate Definition, Codification and

	Inventorying of Rare Diseases including Information and Training Panel III: Clinical and Basic Research In Rare Diseases Panel IV: Standards of Care, Centers of Expertise and Orphan Drugs Panel V: Patient Empowerment and Gathering Expertise at the EU Level
Chairs and Rapporteurs of Workshops	Panel I: Methodology, Governance, Monitoring and Sustainability of a National Plan Chair – Mirosław Zieliński Polish National Forum on the Treatment of Orphan Diseases – ORPHAN Rapporteur – Marcin Mikoś, MD Poznan University of Medical Sciences Panel II: Adequate Definition, Codification and Inventorying of Rare Diseases including Information and Training 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 Rapporteur – Marcin Mikoś, MD Poznan University of Medical Sciences Panel III: Clinical and Basic Research In Rare Diseases 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 Cardinal Stefan Wyszyński University Rapporteur: Marcin Mleczko, Polish Cystic Fibrosis Foundation MATIO Panel IV: Standards of Care, Centers of Expertise and Orphan Drugs Chair: Jacek Graliński, MD, Vice-Director for Clinical Affairs; the Children's Memorial Health Institute in Warsaw

	Rapporteur: Marcin Mikoś, MD **Poznan University of Medical Sciences** **Panel V: Patient Empowerment and Gathering Expertise at the EU Level** **Chair: Paweł Wójtowicz,** **Chairman, Polish Cystic Fibrosis Foundation MATIO** **Rapporteur: Marcin Mleczko,** **Polish Cystic Fibrosis Foundation MATIO**
Attachments	**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**

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) in 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

Undegraduate: 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 3rd 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, phenyloketonuria, 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.

EUROPLAN
European Project for Rare Diseases National Plans Development

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 *Chair: Mirosław Zieliński*
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 *Chair: Prof. Jolanta Sykut-Cegielska, MD, PhD* **Panel III:** Clinical and Basic Research In Rare DIseases *Chair: Prof. Anna Tylki-Szymańska,MD, PhD*
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 *Chair: dr Jacek Graliński, MD* **Panel V:** Patient Empowerement and Gathering Expertise at the EU Level *Chair: Paweł Wójtowicz*
17:00 - 18:00	**Plenary II** Conclusions from panel discussions Closing of the conference

Attachment 3

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

Szanowni 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,

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

„MATIO"
FUNDACJA POMOCY RODZINOM I CHORYM NA MUKOWISCYDOZĘ
30-507 Kraków, ul. Celna 6
tel. 292-31-80, NIP 678-15-61-787

LISTA OBECNOŚCI EUROPLAN Kraków 22.10.2010 r.

L.p	Imię Nazwisko	Jednostka Medyczna Firma	Podpis	Panel 1	Panel 2	Panel 3	Panel 4	Panel 5
1	Paweł Wójtowicz	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę		■				
2	Anna Narowska	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę	[signature]	■				
3	Marcin Mleczko	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę	[signature]			■		
4	Bożena Dziubecka	Bayer Schering Pharma	[signature]					
5	Krystyna Abramska	Polskie Towarzystwo Walki z Kalectwem	[signature]	■		■	■	
6	Ewa Horodycka- Talarek	Polskie Towarzystwo Walki z Kalectwem	[signature]	■	■			■
7	Joanna Girulska-Michalik	Stowarzyszenie Rodzin z Chorobą Fabry,ego	[signature]		■			■
8	Roman Michalik	Stowarzyszenie Rodzin z Chorobą Fabry,ego	[signature]		■			■
9	Iwona Figurska	Shire Polska Sp.z.o.o.	[signature]					
10	Łukasz Szmygel	Stowarzyszenie Pomocy Osobom z Zespołem Williamsa	[signature]			■		■
11	Marta Tomczyk	Polskie Stowarzyszenie z Nadciśnieniem Płucnym	[signature]		■		■	
12	Paweł Szymański	Polskie Stowarzyszenie z Nadciśnieniem Płucnym	[signature]		■		■	
13	Mariusz Ołtarzewski	Instytut Matki i Dziecka	[signature]					
14	Dominik Pawliński	Fundacja Pro Homine Promovendo	[signature]					
15	Teresa Matulka	Stowarzyszenie Chorych na Mukopolisacharydozę i Choroby Rzadkie	[signature]			■		
16	Czesława Grulich	Stowarzyszenie Chorych na Mukopolisacharydozę i Choroby Rzadkie	[signature]				■	
17	Katarzyna Parafianowicz	Fundacja Serce Dziecka				■		■
18		Fundacja Serce Dziecka						

19	Dorota Sienko	Stowarzyszenie Rodzin z Chorobą Gaucher,a	[signature]		■		■	■
20	OLIMPIA SIEŃKO	Stowarzyszenie Rodzin z Chorobą Gaucher,a (os. tow.)	[signature]		■		■	■
21	Krzysztof Knapik	Stowarzyszenie Debra Polska Kruchy Dotyk				■		■
22		Stowarzyszenie Debra Polska Kruchy Dotyk						
23	Roman Michalik	Stowarzyszenie Rodzin z Chorobą Fabry,ego						
24		Stowarzyszenie Uratujmy Życie						
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28	Dorota Kołodziejczyk	Zespół Pompe,go	[signature]					
29		Polskie Towarzystwo Walki z Kalectwem						
30	Tomasz Szelągowski	Federacja Pacjentów Polskich						
31	Stanisław Maćkowiak	Ars Vivendi						
32		Ars Vivendi	Górecka Magdalena					
33	Maria Piętak-Frączek	Urząd Miasta Krakowa						
34	Magdalena Skórniewska	Nutricia	[signature]					
35	Anna Furmaniak		[signature]					
36	Guillaume Flaus		[signature]					
37	Roman Sadzuga	Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka	[signature]					
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39	Artur Jarczyszyn	Fundacja Centrum Leczenia Szpiczaka w Krakowie						
40	Christel Nourissier	EURORDIS/ EUROPLAN	[signature]					
41	Yan Le Cam	EURORDIS/ EUROPLAN						
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43	Jolanta Sykut-Cegielska	Centrum Zdrowia Dziecka i ~~Matki~~ Warszawa	[signature]					
44	Anna Tylki-Szymańska	Centrum Zdrowia Dziecka i Matki Warszawa	[signature]					
45	Jacek Graliński	Centrum Zdrowia Dziecka i Matki Warszawa	[signature]					
46	Wojciech Cichy	Uniwersytet Medyczny Poznań						
47	Marcin Mikoś	Uniwersytet Medyczny Poznań						
48	Natalia Kobylska Dubiel	Uniwersytet Medyczny Poznań						
49	Maria Libura	Polskie Stowarzyszenie Pomocy Osobom z Zespołem Pradera-Willego	[signature]			■	■	
	Jan Kawalec	Stowarzyszenie Marfan Polska	[signature]					
50	Maria Talar		Maria Talar					
51	Monika Sołkowska		M. Sołkowska					
52		Małopolski Urząd Wojewódzki	[signature]					
53	Anastasiia Gavrilova	stop Hepatits / Ukraina						
54	Agnieszka Zakrzewska							
55	Monika Wołek							
56	Luiza Legucka							
57	Karolina Woziwodzka							

58	Alina Sobczak							
59	Alexandre Szypulski		[signature]					
60	Irena Sękal		[signature]					
61	Stanisław Sitko	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę	[signature]					
62	DOROTA KAŃCZAK		Dorota [signature]					
63	ANNA NENKO		Nenko Anna					
64	SYLWIA SOŁKOWSKA		S. Sołkowska					

39	Artur Jarczyszyn	Fundacja Centrum Leczenia Szpiczaka w Krakowie						
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65	MARIA DARSKA	CZŁONEK POLSKIEGO TOWARZYSTWA PSYCHOLOGICZNEGO	[signature]					
66	MICHAŁ RDZANEK	BIURO PROMOCJI UJ	[signature]					
67	Piotr Wilczek	Grupa AOS	[signature]					
68	Magda Kreka	Stowarzyszenie Przedstawicieli Producentów Leków Sierocych	Kreka					
69	MAREK BODZIOCH	Instytut Pediatrii / Zakład Neurogenetyki	[signature]					
70	PAWEŁ KRYSIAK	BIO MARIA / SPPLS	[signature]					
71	Andrzej Pozowski	A PeProjekt	[signature]					
72	KATARZYNA KLINCIAR	Instytut Pediatrii	[signature]	PANEL ZIELONY				
73	Jolanta Wodok	PULS MEDYCYNY	[signature]					
74	ELŻBIETA BOREK	DZIENNIK POLSKI	[signature]					
75	MATEUSZ JAGŁA	INSTYTUT PED. ATTEN	[signature]					
76	FIGLESZ	Kl Neurologii	[signature]					
77	JONAK	Kl Neurologii						
78	Barbara Krawczyk		B. Krawczyk					
79	Sylwia Krawczyk							
80	[illegible]	Szpital Dziecięcy	[signature]					
81								
82								
83	Legenda: kolor zielony: panel 1,2,5		■					
84	kolor czerwony: panel 3,4		■					

FUNDACJA POMOCY ... I CHORYM NA MUKOW... 30-507 Kraków, ul. ... tel. 292-31-80. NIP 678-...

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58	Alina Sobczak							
59	Alexandre Szypulski							
60	Irena Sękal							
61	Stanisław Sitko	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę						
62	Sylwia Sołkowska							
63	Dorota Kaczak							
64	Anna Nenko							

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65	MARIA DARSKA	POLSKIE TOWARZYSTWO PSYCHOLOGICZNE						
66	MICHAŁ [illegible]	BIURO PROMOCJI						
67	Piotr Wilach	Grupa AOS						
68	Magda Knefel	Stowarzyszenie Dziedziczonej Padaczki [illegible]						
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70	PAWEŁ KRYSIAK	MO MARIA / SPPLS						
71								
72	Andrzej Bżarycki	APeProjekt						
73	KATARZYNA HENOYAN	Instytut Pediatrii						
74	Jolanta Hodor	PULS MEDYCYNY						
75	ELŻBIETA BOREK	DZIENNIK POLSKI						
76	MATEUSZ JAGŁA	INSTYTUT PEDIATRII						
77	Anna [illegible]	47						
78	SŁOWIK AGNIESZKA	Klinika Neurologii						
79	JOANNA PERA	Klinika Neurologii						
80	Barbara Krawczyk							
81	Sylwia Krawczyk.							
82								
83	Legenda: kolor zielony: panel 1,2,5							
84	kolor czerwony: panel 3,4							

FUNDACJA ... I CHORYM NA MUKOWISCYDOZĘ 30-507 Kraków, ul. ... tel. 292-31-80. NIP 678-...

LISTA OBECNOŚCI EUROPLAN Kraków 22.10.2010 r.

L.p	Imię Nazwisko	Jednostka Medyczna Firma	Podpis	Panel 1	Panel 2	Panel 3	Panel 4	Panel 5
1	Paweł Wójtowicz	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę						
2	Anna Narowska	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę						
3	Marcin Mleczko	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę						
4	Bożena Dziubecka	Bayer Schering Pharma						
5	Krystyna Abramska	Polskie Towarzystwo Walki z Kalectwem						
6	Ewa Horodycka- Talarek	Polskie Towarzystwo Walki z Kalectwem						
7	Joanna Girulska-Michalik	Stowarzyszenie Rodzin z Chorobą Fabry,ego						
8	Roman Michalik	Stowarzyszenie Rodzin z Chorobą Fabry,ego						
9	Iwona Figurska	Shire Polska Sp.z.o.o.						
10	Łukasz Szmygel	Stowarzyszenie Pomocy Osobom z Zespołem Williamsa						
11	Marta Tomczyk	Polskie Stowarzyszenie z Nadciśnieniem Płucnym						
12	Paweł Szymański	Polskie Stowarzyszenie z Nadciśnieniem Płucnym						
13	Mariusz Ołtarzewski	Instytut Matki i Dziecka						
14	Dominik Pawliński	Fundacja Pro Homine Promovendo						
15	Teresa Matulka	Stowarzyszenie Chorych na Mukopolisacharydozę i Choroby Rzadkie						
16	Czesława Grulich	Stowarzyszenie Chorych na Mukopolisacharydozę i Choroby Rzadkie						
17	Katarzyna Parafianowicz	Fundacja Serce Dziecka						
18		Fundacja Serce Dziecka						

19	Dorota Sienko	Stowarzyszenie Rodzin z Chorobą Gaucher,a	[illegible]
20	OLIMPIA SIEŃKO	Stowarzyszenie Rodzin z Chorobą Gaucher,a (os. tow.)	Sieńko
21	Krzysztof Knapik	Stowarzyszenie Debra Polska Kruchy Dotyk	
22		Stowarzyszenie Debra Polska Kruchy Dotyk	[illegible]
23	Roman Michalik	Stowarzyszenie Rodzin z Chorobą Fabry,ego	
24		Stowarzyszenie Uratujmy Życie	
25		Stowarzyszenie Uratujmy Życie	[illegible]
26		Stowarzyszenie Uratujmy Życie	
27		Stowarzyszenie Uratujmy Życie	
28	Dorota Kołodziejczyk	Zespół Pompe,go	[illegible]
29		Polskie Towarzystwo Walki z Kalectwem	
30	Tomasz Szelągowski	Federacja Pacjentów Polskich	[illegible]
31	Stanisław Maćkowiak	Ars Vivendi	
32		Ars Vivendi	Odrechie Magdalena
33	Maria Piętak-Frączek	Urząd Miasta Krakowa	[illegible]
34	Magdalena Skórniewska	Nutricia	[illegible]
35	Anna Furmaniak		[illegible]
36	Guillaume Flaus		[illegible]
37	Roman Sadzuga	Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka	[illegible]
38		Fundacja Centrum Leczenia Szpiczaka w Krakowie / Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka	[illegible]

39	Artur Jarczyszyn	Fundacja Centrum Leczenia Szpiczaka w Krakowie	
40	Christel Nourissier	EURORDIS/ EUROPLAN	[illegible]
41	Yan Le Cam	EURORDIS/ EUROPLAN	
42	Mirosław Zieliński	Krajowe Forum na Rzecz Terapii Chorób Rzadkich ORPHAN	[illegible]
43	Jolanta Sykut-Cegielska	Centrum Zdrowia Dziecka ~~i Matki~~ Warszawa	[illegible]
44	Anna Tylki-Szymańska	Centrum Zdrowia Dziecka i Matki Warszawa	[illegible]
45	Jacek Graliński	Centrum Zdrowia Dziecka i Matki Warszawa	
46	Wojciech Cichy	Uniwersytet Medyczny Poznań	[illegible]
47	Marcin Mikoś	Uniwersytet Medyczny Poznań	
48	Natalia Kobylska Dubiel	Uniwersytet Medyczny Poznań	
49	Maria Libura	Polskie Stowarzyszenie Pomocy Osobom z Zespołem Pradera-Willego	[illegible]
	Jan Kawalec	Stowarzyszenie Marfan Polska	[illegible]
50	Maria Talar	MATIO	Maria Talar
51	Monika Sołkowska	MATIO	M. Sołkowska
52		Małopolski Urząd Wojewódzki	[illegible]
53	Anastasiia Gavrilova	stop Hepatits / Ukraina	
54	Agnieszka Zakrzewska		Agnieszka Zakrzewska
55	Monika Wołek		
56	Luiza Legucka		
57	Karolina Woziwodzka		

58	Alina Sobczak		
59	Alexandre Szypulski	aleks.szypulski@gmail.com	Szypulski
60	Irena Sękal		Sękal
61	Stanisław Sitko	MATIO Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę	Stanis Sitko
62	Dorota Kaciczak		Kaciczak Dorota
63	Anna Nenko		Nenko Anna
64	SYLWIA SOŁKOWSKA		[illegible]

65	MARIA DARSKA	POLSKIE TOWARZYSTWO PSYCHOLOGICZNE	M. Darska
66	MAGDALENA KNAFER	Stowarzyszenie Przedstawicieli Leków Sierocych	[illegible]
67	P. Wilczek	Grupa AOS	P. Wilczek
68	PAWEŁ KRYSIAK	BioMaris / SPPLS	[illegible]
69	ANDRZEJ POŻARYCKI	AR Projekt.	[illegible]
70	MAREK BODZIOCH	INSTYTUT PEDIATRII	[illegible]
71	~~[illegible]~~		
72	KATARZYNA KRACIAR	Instytut Pediatrii	Kraciar
73	Jolanta Paster	PULS MEDYCYNY	[illegible]
74	ELŻBIETA BOREK	DZIENNIK POLSKI	Borek
75	Mateusz Fros	INSTYTUT PEDIATRII CMUJ	[illegible]
76	Bar Knapik	UJ	[illegible]
77	Agnieszka [illegible]	CMUJ	[illegible]
78	Joanna [illegible]	CM UJ	[illegible]
79	Barbara Krawczyk	UJ	B. Krawczyk
80	Sylwia Krawczyk	UJ	[illegible]
81			
82			
83	Legenda: kolor zielony: panel 1,2,5		
84	kolor czerwony: panel 3,4		

studenci, uczelnie, inni nie NGO

"MATIO" FUNDACJA POMOCY RODZINOM I CHORYM NA MUKOWISCYDOZĘ 30-507 Kraków, ul. Celna 6 tel. 29?-?1-80, NIP 678-16-61-787

Lista obecności EUROPLAN Kraków 22.10.2010 r.

Lp	Imię i Nazwisko	Uczelnia	Adres	Podpis
1	Paulina Paciorek	CM UJ	Rzeźba, ul. Krakowska 42, 30-199 Kraków	Paciorek
2	Barbara Kwaciszewska	CM UJ	ul. Spółdzielcza 8/26 31-542 Kraków	Kwaciszewska
3	Luiza Legucka	CM UJ	ul. Sołtyska 218 30-638 Kraków	Luiza Legucka
4	Magdalena Fortuna	CMUJ.	~~[illegible]~~ ul. Zielińskiego 7/10 37-500 JAROSŁAW	Magdalena Fortuna
5	Mariusz Rogozik			
6	Ewa Sarota	CMUJ	ul. Wrocławska 52A/48 30-011 KRAKÓW	Sarota Ewa
7	Barbara Sus	CMUJ	ul. Stara Kolonia 41 47-133 Jemielnica	Sus

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8	Agata Włoszczyńska		Os. Piastów Bl. 3/12 47-100 Strzelce Op.	Agata Włoszczyńska
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10	Emilia Socha	CMUJ	Kłokoczyn 167 32-070 Czernichów	Socha Emilia
11	Justyna Socha	CMUJ	Kłokoczyn 167 32-070 Czernichów	Socha Justyna
12	Olga Art	CMUJ	ul. K. Wallenroda 59/56 30-867 Kraków	Art Olga
13	Katarzyna Chrabąszcz	CMUJ	chrabaszcz1988@gmail.com ul. Żuławskiego 16/1 31-145 Kraków	Chrabąszcz Katarzyna
14	Justyna Piestrzonek			
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16	Joanna Zmarzlik	CMUJ	j.zmarzlik@wp.pl ul. Konstytucji 3 Maja 6E 28-200 Staszów	Joanna Zmarzlik
17	Magdalena Pietrzyk	CMUJ	pietrzyk2007@wp.pl ul. Szwedzkiego ~~[illegible]~~ 4/49 31-417 KRAKÓW	Magdalena Pietrzyk

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18	Przemysław Sieradzki	CMUJ	Rzozka, ul. Sucha 71 30-198 Kraków	[illegible]
19	Agnieszka Kargul	CMUJ	ul. 1-go Maja 22A 27-500 OPATÓW	Kargul Agnieszka
20	Anna Krawiel	CMUJ	ul. Słomnicka 26 16-124 Sidra	Krawiel
21	Karolina Kuca			
22	Bartosz Domin	CM UJ	ul. Posada 20 32-555 Zagórze	Bartosz Domin
23	Bartosz Rzyman			
24	Dominika Michalczewska			
25	Urszula Kulczyk			
26	Karolina Kosibowicz	CMUJ	ul. Orzeszkowej 5/11 31-065 Kraków	Kosibowicz
27	Żaneta Czernecka	CMUJ	ul. Smoleńsk 26/10 31-112 KRAKÓW	Czernecka

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28	Ewa Obrał	CM UJ	ul. Starokowska 17/d 31-0[illegible] Kraków	Obrał Ewa
29	Eliza Zawadzka	CMUJ	ul. P.C.K 7 m 17 26-600 RADOM	Zawadzka
30	Dagmara Faber			
31	Ludwik Odrzywołek			
32	Ewelina Woderska			
33	Monika Wołek		Klimontów 268 32-112 Klimontów	Monika Wołek
34	Karolina Woziwodzka		Sarego 18/7 31-047 KRAKÓW	Karolina Woziwodzka
35	Maria Talar		Okulickiego 51/44 K-ów	Talar Maria
36	Sylwia Sołkowska		Okulickiego 57/39	S. Sołkowska
37	ANNA NENKO		KURCZABA 37/42 30-868 KRAKÓW	Nenko Anna

zostawić w Fundacji

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38	DOROTA KACICZAK		Chrosna 138 32-084 MORAWICA	Kaczmarek
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40	Agnieszka Tomczyk		ul. Rakowicka 21/2 31-510 Kraków	Tomczyk
41	Magdalena Wodarz		Kraków Stanisława 66/13 31-038	Wodarz
42	Agnieszka Lewkowicz	Szpital w Prokocimiu	KRAKÓW	Lewkowicz
43				
44				
45				
46				
47				

– do odbioru fundacji