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Partners:

Dutch Steering
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Polish stakeholders sign petition for a National Plan for Rare Diseases during the European Conference on Rare Diseases (ECRD Krakow 2010)

PRESS RELEASE – May 18, 2010. Polish stakeholders acting on behalf of rare disease patients met on the first day of the European Conference on Rare Diseases (ECRD 2010 Krakow) on May 15, to agree on a petition to the government to establish a National Plan for Rare Diseases in Poland.

In accordance with the ideas presented at the 5th European Conference on Rare Diseases and taking into account the recommendations of the European Commission along with the position of the Committee on Human Development of the Polish Academy of Sciences (PAN), 20 Polish doctors, scientists and patient representatives present at the meeting have put forward a motion to the Minister of Health to establish and organise a National Programme for Rare Diseases in Poland.

*- ECRD is the best occasion for the current representatives of organisations acting on behalf of patients affected by rare diseases and representatives of the medical environment to meet and jointly agree on their position on rare diseases – **said Prof Wojciech Cichy from Poznan University of Medical Sciences.** – We predict that in three months time the first meeting of the Team for Rare Diseases shall take place, during which the first working groups shall be appointed to define rules in order to fulfill the main objectives of the National Plan – **added Prof Cichy.***

Participants to the meeting granted their full support to the Team for Rare Diseases, appointed by the Minister of Health, on its current activities and on the possibility to accomplish tasks in accordance with the recommendations of the European Union. All these activities are to lead, as soon as possible, to the foundation of the National Programme for Rare Diseases. They also suggested following the EuroPlan guidelines as the European platform to accomplishment of the aforementioned goals.

*- We hope that this agreement shall result in the foundation of a National Programme for Rare Diseases before 2013, thanks to which the quality of patients life shall improve earlier than predicted by the European Commission – **said Paweł Wojtowicz, the President of MATIO Foundation for Help to the Cystic Fibrosis Sufferers and their Families.***

The Polish stakeholders who met at the ECRD Krakow 2010 are:

1. *Prof Tomasz Grodzicki* – Dean of the Medical Faculty Jagiellonian University, Krakow.
2. *Prof Wojciech Cichy* – Department of Pediatric Gastroenterology and Metabolic Diseases University of Medical Sciences in Poznan,
3. *Prof Anna Tylki-Szymanska* – Clinic for Metabolic Diseases, Endocrinology and Diabetes 'The Children's Memorial Health Institute',
4. *Prof Ewa Bernatowska* – Department of Gastroenterology, Hepatology and Immunology, 'The Children's Memorial Health Institute',
5. Prof *Janusz Limon* – Department of Biology and Genetics of the Medical University of Gdansk,
6. *Prof Grzegorz Węgrzyn* – Department of Molecular Biology, University of Gdańsk,
7. *Dr hab. n. med. Jolanta Sykut-Cegielska* - Clinic for Metabolic Diseases, Endocrinology and Diabetes, 'The Children's Memorial Health Institute' ORPHANET Poland,
8. *Dr Bożena Dębowska* – Baginska - 'The Children's Memorial Health Institute',
9. *Dr Agnieszka Sobczynska – Tomaszewska* – GENOMED,
10. *Dr Mariusz Oltarzewski* – Screening Unit, Institute of Mother and Child,
11. *Dr Daniel Zielonka* – Department of Social Medicine, University of Medical Sciences in Poznan,

12. *Paweł Wojtowicz* - MATIO Foundation for Help to Cystic Fibrosis Sufferers and their Families,
13. *Marcin Miko* – doctor, representative of MATIO Foundation for Help to the Cystic Fibrosis Sufferers and their Families,
14. *Stanisław Mackowiak* –‘Ars Vivendi’ Association for Help to Phenylketonuria (PKU) and Rare Diseases Sufferers,
15. *Hanna Milczarek* - The Dina Radziwillowa Child’s Heart Foundation,
16. *Mirosław Zielinski* – ORPHAN National Forum to Rare Diseases Therapy,
17. *Maria Libura* - Prader-Willi Syndrome Association,
18. *Teresa Matulka* - MPS and Related Diseases Society,
19. *Ewa Golebiewska* – Polish Huntington’s Disease Association,
20. *Ewa Frajs* – Marfan Association in Gdynia.

Participants of the Conference stressed that the National Programme for Rare Diseases should include, among others, the following activities :

- Prevention, early diagnosis and screening
- Preparation of patient registries, for different rare diseases groups
- Specialist medical care
- Funding of treatment
- Social care
- Information and education

ECRD represents the most influential event in the world of rare diseases. It is a unique forum gathering all rare diseases, all European countries and all stakeholders (academics, health care professionals, industry, policy makers and patient representatives) to discuss key policies and actions to improve the lives of those affected.

ECRD is organised by The European Organisation for Rare Diseases (EURORDIS) in partnership with Rare Disorders Denmark, the National Health Institute (UK) and the Fundacio Doctor Robert, Autonomous University of Barcelona. It is primarily supported by the Public Health Programme of the European Commission, co-funded by CSL Behring, Novartis and Sigma Tau, with additional sponsorship from 10 other companies.

To see the Programme and for more information, visit: www.rare-diseases.eu

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Rare Diseases

A rare disease is considered as that when it affects less than one in 2000 people. Rare diseases are chronic, progressive, degenerative, and of the life-threatening. There is no cure today for the 6000 – 8000 rare diseases identified, of which 75% affect children. Due to their rareness information is scarce and research is insufficient. People affected by rare diseases face common challenges such as diagnosis delay, misdiagnosis, psychological burden and lack of practical support for everyday life. About 30 million people suffer from a rare disease in Europe today.

About EURORDIS

The European Organisation for Rare Diseases (EURORDIS) represents more than 400 rare disease organisations in 43 countries, covering more than 1,000 rare diseases. It is therefore the voice of the 30 million patients affected by rare diseases throughout Europe.

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe. It is supported by its members and by the French Muscular Dystrophy Association (AFM), the European Commission, and corporate foundations and the health industry. EURORDIS was founded in 1997. More information on: www.eurordis.org