



European Society for Phenylketonuria  
and Allied Disorders treated as Phenylketonuria  
(E.S.PKU)

# Annual Report 2010

Cooperation – Networking – Success



# Annual Report 2010

**Tell me about the past,  
and I will perceive the future.**

Konfuzius, Chinese philosopher, 551–479 B.C.



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## Chapter I: Political work

### Introduction

The treatment of PKU is constantly developing. New products are developed for the dietary treatment and new pharmaceutical treatment strategies are coming up. Even if health and social affairs are more and more concentrated in European politics, we still have to deal with national authorities for daily life issues.

### Reimbursement of Kuvan® in Sweden

It is policy of E.S.PKU, that every patient with PKU or any allied disorder must have access to all treatment options, which are individually appropriate under medical control. This access shall not be limited by origin, age or genotype and include all treatment aspects, even those beyond phe levels.

In this direction, we support all efforts of our member associations and others. Exemplary is the co-ordinated action to make the Swedish government change their minds, who decided not to reimburse Kuvan® as treatment for PKU in Sweden. In close cooperation with the Swedish PKU association, our Scientific Advisory Board and other associations like EURORDIS, we sent petitions to the Swedish health ministry. Even if we have not been successful yet, this example shows the importance of implementation of E.S.PKU in strong networks for a better lobby work and the interests of all patients.

### European food labelling

About two years ago, we made an agreement on a suitable quantitative labelling of aspartame on regular foods with the International Sweeteners Association (ISA). Unfortunately, the members of ISA did not accept this agreement and took efforts at the EU-level to remove the mandatory labelling that aspartame contains a source of phenylalanine.

Due to our efforts, which have been supported by some others, we could influence the EU after the last European election. We reached the interim result that the sentence is still an element in the new labelling regulations.

### Implementation of E.S.PKU in strong networks

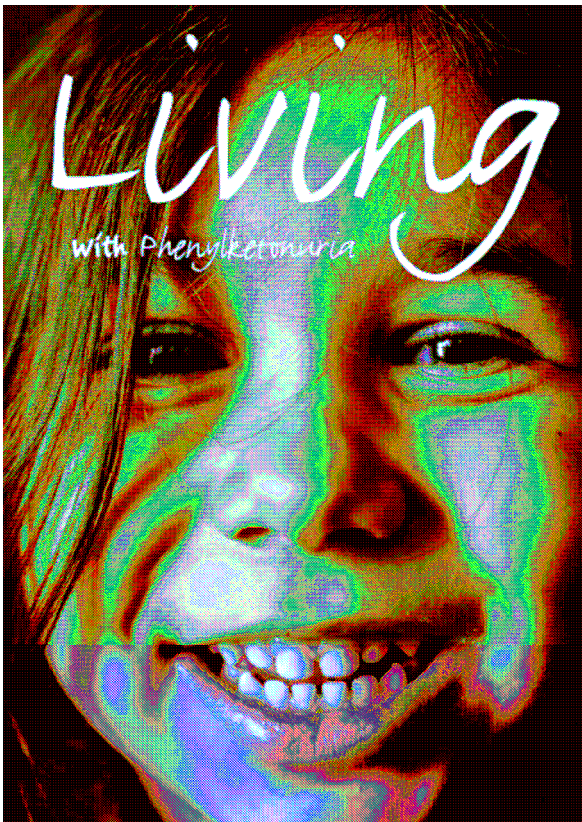
The above listed political jobs, which we have been performing within the past year(s), are one of the reasons, why E.S.PKU is actually applying for a membership in EURODIS and other associations, which might be of use for our interests.

## Chapter II: Publications

### E.S.PKU News

In summer 2010, E.S.PKU edited another issue of the E.S.PKU News Magazine. Summaries of the 2009 Annual E.S.PKU Conference, an interview on untreated compared with treated PKU, a book presentation and some recipes were collected in a magazine containing 28 pages. 500 copies have been distributed via the E.S.PKU member associations and the advertising partners.

### A new resource for the PKU community: “Living with PKU”



Living with PKU contains real stories about people living with PKU, who are sharing experiences from all around the world to make this rare condition less isolating. Some people have struggled with PKU and others have found living with the condition has minimal impact on their lives. There are stories from people of all age groups: parents, teenagers and adults, as well as from different countries around the world. One thing becomes very clear throughout all the stories: The importance of a supportive family and access to information about the condition and other people living with PKU.

Living with PKU was developed as a joint effort by the European Society for Phenylketonuria and Allied Disorders (E.S.PKU) and Merck Serono. Both E.S.PKU and Merck Serono are committed to helping people with PKU controlling their blood phenylalanine (Phe) levels in the way that is right for them as individuals. Besides the commitment to PKU patients, E.S.PKU and Merck Serono are

supporting the healthcare professionals, who manage PKU.

The book is set up in seven languages: English, French, German, Spanish, Italian, Dutch and Turkish. It is available at the E.S.PKU head office or via the E.S.PKU members.

“Living with PKU” was presented to the public at a media briefing, conducted by BBC-Newsreader Nicholas Owen, at the eve of the 2<sup>nd</sup> PKU Group Symposium in Munich, Germany, at January 21<sup>st</sup> 2010 in presence of about 20 international scientific journalists.



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## Chapter III: Public relations

### E.S.PKU website: [www.espku.org](http://www.espku.org)

Internet is the most important instrument for societies like E.S.PKU to present their work and aims to the public. Therefore, E.S.PKU already decided in 2009 to launch a new website, which was presented at the 2009 Annual E.S.PKU Conference.

Since then, further items have been included in the website: It is a multilingual website, presenting in English, French, German, Spanish and Turkish. All translations are made honorary by voluntary working people from the various countries. We are still looking for someone from Italy, who will take care of the Italian translation or our website articles.

Within the first year, there were more than 50.000 viewers counted on our website, which proofs the high interest of the users. Especially the online scientific presentations are visited very frequently.

The website offers the opportunity to all partners of E.S.PKU to inform about activities and to make contact to the PKU community.

Information on actions and initiatives of E.S.PKU are available as well, such as the Annual E.S.PKU Conference, including an online registration form. E.S.PKU also provides this online registration form to all E.X.PKU members for their own use.

### Conference Image Film

Supported by Merck Serono, our main sponsor of the E.S.PKU Annual Conference 2009, a professionally taped and cut image film was produced during the E.S.PKU Conference 2009 in Turkey. Within about 5 minutes, this film gives an impression of the atmosphere of an E.S.PKU Conference. It is published at the internet (youtube) and linked to the E.S.PKU website.



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## Chapter IV: Administration and Organisation

### E.S.PKU Conferences

So far, there was an alternating conference concept (delegates- and family-meetings). Now, the E.S.PKU Executive Board decided to open all future Annual Conferences to everyone: patients, families, delegates of the E.S.PKU members and professionals.

Future conferences, beginning with the upcoming event in Copenhagen, Denmark, 2010, offer separated and combined programmes for patients and their family members, as well as for professionals (health care providers) and the delegates of the E.S.PKU member organisations, at the best level possible.

By concentrating the acquisition of international sponsors at the E.S.PKU board level, financial risks are minimized for local organisers. By implementing a co-ordinated teamwork between E.S.PKU Executive Board, the board of the E.S.PKU Scientific Advisory Committee, as well as the local organizing E.S.PKU member association, the quality of the conferences shall be improved and reach a high professional level comparable to other (scientific) conferences. At the same time, responsibilities and burdens for the local organizing E.S.PKU member association will decrease.

The unique character of the conference, including the get together between health care providers and patients, will remain unchanged.

### Support of scientific work

As a result of the fund-raising activities during the E.S.PKU Annual Conferences (and of member associations activities), E.S.PKU has to decide on what projects should be supported. As the amount will not be as high as originally expected in short time, an application procedure for E.S.PKU funds has been set up by the executive board.

## Chapter V: Further activities

### Take charge of Phe: European survey of patients, families and healthcare professionals treating PKU

A European-wide survey was carried out via the E.S.PKU website to understand the attitudes and behaviours of patients, families and healthcare professionals treating PKU, in 2009. Up to date, this was the largest and only research of this kind. The survey aimed to identify gaps in service provision and opportunities to improve services for people living with PKU across Europe.

While the research showed some similarities in the way patients, parents and healthcare professionals approached PKU, there were also found some differences. The physicians thought that the three main challenges of living with PKU were the temptations of eating normal food, the taste of supplements and low-phe foods as well as the number of foods not allowed in the PKU diet. In contrast, the patients found that travelling from home and the need to plan everything in advance were the biggest challenges, followed by the temptation of normal food.

The most alerting outcome of the survey was: Patient results also show us that 75% of patients stray from their diet as opposed to the presumption by health-care professionals that 55% strayed from their diet. And this under the preposition that those who took part and answered the survey honestly, are only the top of the ice-berg.

The research was carried out in the second half of 2009 and included healthcare professionals from across Europe, as well as patients and their families.





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## Chapter VI: Conclusions and Consequences

### Conclusions

Beyond successful work, this annual report 2010 shows the importance of networking. Successful lobbying for the interests of our members and all PKU patients and patients with allied disorders needs cooperation with other parts of societies, both outside and inside E.S.PKU.

Nevertheless: Whereas E.S.PKU is more and more successfully linked with researchers and health-care providers, political groups and other organisations outside E.S.PKU, the cooperation between the E.S.PKU and its members is still weak. With a few exceptions, E.S.PKU did not succeed to facilitate network activities and common actions with and between its member associations up to now. This needs to be more than a consistent offer from the E.S.PKU to its members: This offer must be actively accepted by the E.S.PKU members, too.

Exemplary for this is the book "living with PKU": Only 3 out of 25 member associations ordered their package of free copies, whereas we are regularly contacted by patients, who are interested in getting this informative book. And only a few members signed and returned the supportive letters for Sweden in their fight for reimbursement of Kuvan®.

### Consequences

The E.S.PKU Executive Board will constantly follow the road as successfully taken now, aimed to facilitate the best networks and lobbying for the benefit of the patients.

Furthermore, we will increase our focus on the patients and their families, as long as the networking between our member associations is not improving. To avoid any competition between E.S.PKU and national PKU self-care associations, these programmes and activities must offer added value for the E.S.PKU member societies as well.

Internal concordance is a main key for E.S.PKU to become a really strong and successful speaking tube for the interests of patients and member associations.

**The future is in (y)our hands.**



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## Impressum

This Annual Report 2010 was presented to the delegates of the attending member associations of E.S.PKU at the 2010 General Meeting of E.S.PKU, held on October 22<sup>nd</sup>, in Copenhagen, Denmark.

It gives insight into the main working fields of E.S.PKU from November 2009 until October 2010, without laying claim to completeness.

This Annual Report 2010 is published at [www.espku.org](http://www.espku.org)

On behalf of the E.S.PKU Executive board:

David Abeln  
(President)

Tobias S. Hagedorn  
(Secretary)

**European Society for Phenylketonuria  
and Allied Disorders treated as Phenylketonuria  
(E.S.PKU)**

is a non-profit organisation promoting exchange of information about phenylketonuria (PKU) and allied disorders of amino acid metabolism.

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E.S.PKU

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The European Society for Phenylketonuria and allied disorders treated as Phenylketonuria is a non-profit organisation with members in the following countries:

Austria

Italy

Montenegro

Croatia

Latvia

Slovakia

Czech Republic

Lithuania

Slovenia

Denmark

Moldova

Spain

Estonia

Norway

Sweden

Germany

Poland

Switzerland

Hungary

Portugal

The Netherlands

Iceland

Romania

Turkey

Ireland

Serbia

United Kingdom

**Executive Board:**

President: Mr. David Abeln, The Netherlands

Vice-President: Miss Dinah Lier, Switzerland

Treasurer: Mr. Maarten Criem, Belgium

Secretary: Mr. Tobias S. Hagedorn, Germany

**Board of the Scientific Advisory Committee:**

Chairman: Dr. Francjan J. van Spronsen, The Netherlands

Vice-Chairman: Dr. Maria Gizewska, Poland

Secretary: Mrs. Kirsten Ahring, Denmark

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