



E.S.P.K.U

newsletter

1st edition
2011

FIRST ESPKU NEWSLETTER

Dear Members of ESPKU,
at the ESPKU Annual Conference 2010 in Denmark, the delegates expressed the wish to receive short newsletters via email throughout the year. This idea was picked up by the ESPKU Executive Board and this first newsletter has been set up. We kindly ask you to make sure that the information of this newsletter is being forwarded to the members of your association – put it on your homepage, print it in your magazine or include it in your own newsletter.

This newsletter is a new project. To improve it and keep it alive, we will need your support and feedback – please feel free to send us short information about activities of your association, interesting news or comments on articles of previous newsletters. Inputs for future newsletters can be sent to us by email.

Thanks for your feedback and support.
On behalf of the ESPKU Executive Board,
Dinah Lieber
(ESPKU vice-president)

LOOKING BACK: ESPKU ANNUAL CONFERENCE 2010 IN DENMARK



A daily newsletter was printed during the ESPKU Annual Conference in Denmark. This newsletter included more information about daily highlights as well as the programme that was run by the professionals. Digital versions of the newsletters are available on the website of ESPKU. Please, use the conference newsletters to inform the PKU patients and their families in your country.

Furthermore, a little film was made at the conference. It is published on Youtube:

<http://www.youtube.com/watch?v=V1dSbVOfxi0>

If you show this film to your members at the annual meeting of your association it gives the opportunity to them to get to know to the ESPKU and its activities a little better.



EURORDIS

The ESPKU has applied for membership on the Eurordis organisation (www.eurordis.org).

EURORDIS is a non-governmental patient-driven alliance of patient organizations 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.



SWEETENER: NEOTAME

Neotame is an artificial sweetener made by NutraSweet that is between 7,000 and 13,000 times sweeter than sucrose (table sugar). In the European Union, it is known by the E number E961.

Neotame is moderately heat stable and extremely potent. Neotame is rapidly metabolized and completely eliminated and does not accumulate in the body.

It is chemically similar to the artificial sweetener aspartame but is used at vastly lower levels and is more stable.

Chemically, it has a 3,3-dimethylbutyl group attached to the amino group of the aspartic acid portion of the molecule. Peptidases, which would typically break the peptide bond between the aspartic acid and phenylalanine moieties, are effectively blocked by the presence of the 3,3-dimethylbutyl moiety, thus reducing the production of phenylalanine, thereby making its consumption by those who suffer from phenylketonuria safe.

PKU-REIMBURSEMENT-POLICIES IN EUROPEAN COUNTRIES

Some time ago, the ESPKU Executive Board started to create a list with information about the reimbursement policies in different European countries. So far the list includes this information of 14 countries.

Please, find the list at the following link: <http://www.espku.org/de/pku-in-europe.html>

If your country is not named in the list yet, please send your details to: info@espku.org

Then, your country will be added to the list.

Thank you!



DELEGATES MEETING IN APRIL 2011

The wish to have a more intense contact to delegates of other countries was mentioned by several participants of the ESPKU Annual Conference 2010. Therefore, the ESPKU Executive Board offers the delegates to have an additional meeting in Poland in spring time.

The ESPKU Executive Board meeting and delegates meeting will take place at the Warsaw Marriott Hotel from at 9th April 2011 in Warsaw, Poland. The arrival of the participants shall be Friday, 8th April and departure on Sunday, 10th April 2011.



Please book your room directly at the hotel.

All attending delegates are responsible to book their room themselves. Hotel costs will be approximately 85 Euro per person per night. Information about the hotel can be found on the homepage: <http://www.marriott.com/hotels/travel/wawpl-warsaw-marriott-hotel/>

To organise the meeting, we ask you to send us an email (to info@espku.org) including the following information before 1st March 2011:

- Name of all attending delegates from your association
- Need of low protein foods for PKU patients

We will send out further details regarding the meeting in the first half of March 2011!



SHORT UPDATE: INTERNATIONAL PKU ADULTS MEETING

The 3rd International PKU Adults Meeting is going to take place in Warsaw from SUNDAY, Oct. 9th until THURSDAY, Oct. 13th (ESPKU meeting starts Friday morning).

Please forward this information to your national PKU adults!

Visit <http://www.facebook.com/pkuadultsmeeting>

or write a mail to i-am-pku@hotmail.com for further information & updates!



Dinah, Deborah (both adult PKU patients from Switzerland) and Timon (adult PKU patient from Austria) will offer adults with PKU to meet just before the Annual ESPKU Conference 2011 in Warsaw. We will do sportive and cultural activities as well as workshops. One of the aims of this meeting is also to get adult PKU patients to join the Annual ESPKU Conference and stay in touch with the community.

QUESTIONNAIRE: Q&A WITH A PKU...

Q: Please, tell us a little bit about yourself?

A: Hi, my name is Timon, I'm 25 years old. I do have classical PKU and never went off diet. Last summer I finished my communications- & media-studies with MA. Now I work as a part-time journalist in Vienna. Besides that I'm board-member of the national PKU association in Austria (ÖGAST www.oegast.at) and founding member of the International PKU Adults Meeting (www.facebook.com/pkuadultsmeeting).

Q: Where do you get your low protein products from?

A: I either bake myself, order food from the international PKU companies (SHS, Hammermühle, Balviten, comidaMed) or get some fresh baked low-pro bread from our Viennese bakery „Grimm“. It's a regular bakery which also produces low-pro breads when you order them in advance - a service which is actually quite awesome and irregular.

Q: Do you have many contacts among other PKU patients?

A: Definitely! Not only because of my work in the national PKU association but also internationally - I do travel a lot and feel very lucky to have many international PKU contacts as well.

Q: How is that arranged?

A: We keep in touch at our national annual meetings, at the ESPKU annual meeting, at our International Adults Meeting, at baking classes or just like that via phone, mail or social networks such as facebook or the international PKU-board (www.pkuboard.info)

Thank you very much for the pleasant talk!



Contact info of our interview partner:

Contact info:
timon.schaffer@oegast.at

In the next edition of the newsletter you will find the same questions answered by another PKU patient. If you know any PKU patients from your country, who are interested in filling in this questionnaire, please let us know.

We are looking forward to introducing many patients from different countries to you.



Contact:

info@espku.org
www.espku.org