VHL Europa Newsletter

VHL symposium in Madrid

December 2014

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"Best wishes in a healthy 2015"

Child is born, well almost!

I was hoping I could share the news that the foundation of the European von Hippel-Lindau Federation (VHL Europa) was official and the signatures were under the official founding document at the notary. We are getting close, but are not there yet. This didn't stop VHL Europa from moving forward.

In this newsletter we take a short moment to look back but also share with you all great initiatives/projects which are currently taken place.

I like to thank everybody for all the efforts in setting up this great federation and wish you all the best in a healthy 2015.

Ronald Westerlaken

president@vhl-europa.org

Beginning of VHL-Europa

Since three years representatives from various national VHL patient organizations met to discuss common issues and help individuals in other countries to set up their own national organization. All with the strong belief that an European organization formed by national VHL patients associations that share the same aims would be a more effective way to serve the needs and support patients and their carers of this rare genetic tumor disease.

On October 22nd, the evening before the official start of the international VHL Symposium in Madrid, representatives of France, Germany, Greece, Hungary, Italy, the Netherlands and Spain met and founded the European VHL (von Hippel - Lindau) Federation. First steps that will be taken is setting up a catalogue for centers of expertise and organizing a symposium for our young adults with VHL in 2015.

VHL Europa's first board:

President: Ronald Westerlaken (The Netherlands)

First banner of foundation

Vice-President: Jean-Joseph Crampe (France)
Secretary: Athina oz Alexandridou (Greece)
Thesaurus: Gerhard Alsmeier (Germany)

The objectives of VHL Europa are

1) Supporting existing national VHL patient organisations and helping to set up new and foster cooperation between these national organizations in Europe and develop a common policy, if possible, between them, and to do everything that is related to this in the broadest sense, either directly and indirectly,

2) Improving situation of people affected with VHL in Europe

3) Promoting and sustaining research

Thanks to EURORDIS who sponsored two of our meetings

Ongoing projects

Cataloging Expert Centres for VHL

Orphanet (www.orpha.net) has been working with the European Commission in Brussels to establish centrally certified Expert Centres in Europe forrare diseases, such as VHL. In the future, European Funding and Cross-Border Healthcare will only be provided to those hospitals qualifying as an Expert Centre for that disease.

The process began in 2014, with each European country having its own timeline. The Academic Hospital wishing to apply as an Expert Center for VHL has to fill in a detailed survey (15-25 pages!) of their Care Path for VHL patients, the multidisciplinary team by name (and their back-up specialist) dedicated to VHL patients (for example, this will have an eye doctor, a brain/CNS surgeon, an endocrinologist/internist, a pediatrician, a clinical geneticist, a Gastro-intestinal onco-surgeon (specialising in pancreatic tumors), etc).

The research going on at the applying Expert Center needs to be fully described and shown that money is being obtained for research and that research papers are being published. One of the interesting aspects of this process is that the application from the Expert Center is then sent to the national patient organization if possible for evaluation before the committee further considers granting the status Expertise Center. The Patient Organisations also suggest which Centres they think are suitable for their patients[1] needs.

The European Commission has not yet published their evaluation criteria, but it is expected to be a rigorous process with about 50% approval rate for all Centres applying. One project we hope to tackle to generate a list of all the VHL Expert Centres approved by Brussels and presenting them in a comprehensive list for our member VHL affiliates.

Join us!

Whether you are a VHL expert, doctor, national VHL organization, patient or other interested person or party, we need your support!

We have 3 types of memberships:

1) Full members, being national VHL organisations recognized in their country as non profit associations within Europe, independent of authorities, political parties, the pharmaceutical industry and commercial organizations

2) Affiliated members, are individuals from European countries where no National Association for VHL is in existence. An affiliated member may attend all VHL-Europa meetings as observer without the right to vote.

3) Sponsoring members, members can be individuals who support the goals of VHL Europa. They may attend all VHL-Europa meetings as observer without the right to vote.

Together with this newsletter we also send an application form. Choose the right type of membership and apply by filling in the required info and send it back, preferably digital (scanned with signature), to the following email (board@ board@vhl-europa.org)..

Promote us!

For more information, see:
http://ec.europa.eu/health/rare_diseases/european_reference_networks/erf/index_en.htm

It is anticipated that between 1-2 hospitals will qualify per 10 million inhabitants in a given country, although this may vary.

More soon!

Rachel Giles, The Netherlands

International VHL Symposium for Young Adults 2015

Date 31 July – 3 August 2015
Place Utrecht, The Netherlands

We are very pleased to announce the International VHL Symposium for Young Adults 2015. This is the first time this event is being organized, by host country The Netherlands. Several important goals are being aimed during this event. First of all we would like to create the opportunity to network and share global experiences with VHL. Important choices need to be made as a young adult and from psychological point of view, sharing experiences is extremely valuable. Another important part of the program is designed to increase age-specific VHL-related knowledge. VHL-affected young adults carry many responsibilities and by providing up to date information, we want to increase participants' awareness. The program offers a good balance between leisure activities and serious topics, including: *VHL Quiz, interactive VHL related lectures, BBQ, Festival 'De Parade' Utrecht & Jordaan tour in Amsterdam.* Information on subscriptions will be provided ASAP.

Criteria Participants
- 18-27 years
- VHL-affected
- should have sufficient English knowledge to be able to express themselves
- no parents & no partners policy

Any questions or queries? Just4youth@vonhippellindau.nl
Hope to meet you in July 2015! *(if you meet the criteria)*

Barbara Bezemer, The Netherlands

Educating doctors

If you or someone in your family has a VHL disease, screening and treatment by expert doctors, i.e. team of experts, are crucial. They help find disease at its earliest stage. In von Hippel Lindau disease, early diagnosis increases your chance for successful treatment and better quality of life. Surgery, including minimally invasive and laser surgery in some cases, is the main treatment for VHL-associated problems.

Still in many countries special VHL expertise centers are missing and doctors are lacking the special experience for correct treatment of a VHL patient. We like to play an important role as an intermediator and set up the contacts between experienced and unexperienced doctors to share, train and elevate the knowledge about VHL.

Furthermore, handbooks in many cases are written for patients. But are to big and missing the medical terminology and specific content the doctors need. One goal is to create such a general document that will serve the needs for educating doctors about VHL and distribute it to as many relevant hospitals as possible in Europe.

Karina Villar, Spain
Athina oz Alexandridou, Greece (athinakonstantina@gmail.com)

Genetic Testing

Genetic testing for VHL is normally done only once in a lifetime. However families are more often confronted with it, as relatives-at-risk or children have to be tested as well. Therefore it is crucial to have the genetic testing done in a laboratory which works accurate, reliable and quick. To ensure that these criterias apply to the lab in question, it should be participating in a quality assurance program. In Europe "the European Molecular Genetics Quality Network (EMQN)"http://www.emqn.org/emqn/Home is offering such a quality program.

EMQN is a not-for-profit organisation promoting quality in genetic testing by establishing, harmonising and disseminating best practice. They provide accredited (ISO 17043) external quality assessment (EQA) to labs worldwide. EMQN's EQA schemes are designed to test the whole analytical process of molecular genetics laboratory; the ability to interpret data in the light of clinical information supplied with a referral, and to produce a clear and accurate report.

In order to know which laboratories participated in the annual EQA one had to wait fairly long until it was published on orpha.net (www.orpha.net). Goal of this project is to provide this information faster and more reliable about all participating laboratories, so families can have their genetic testing done in a laboratory, which takes part in the EQA.

Gerhard Alsmeier, Germany

More news

Campaign for European Year for Rare Diseases 2019

In 2019, we will celebrate the 20 year anniversary of the adoption of the EU Regulation on Orphan Medicinal Products and the 10 year anniversary of the Commission Communication and Council Recommendation on rare diseases.

The European Year will send a strong public and political message on behalf of the 30 million Europeans who suffer from a rare disease and will raise awareness and encourage researchers to focus on these rare, mostly unknown, seriously debilitating and often life-threatening diseases.

In order to make 2019 the European Year for Rare Diseases, please join the campaign

- by signing up to join the campaign!

- by writing a letter to your national policy makers (template letter)

- by putting the Logo on your website

More information: http://www.eurordis.org/eyrd2019

New Journal

The Journal of Kidney Cancer and VHL (JKCVHL) is an independent, open access, online-only journal that offers a rapid publication platform for novel discoveries in all aspects of kidney cancer and disorders of the von Hippel-Lindau (VHL) gene. JKCVHL will publish original articles and reviews in basic and clinical research, and also case reports. All submitted manuscripts will undergo rigorous peer review.

VHL Symposium 2014 in Madrid

The VHL Symposium 2014 took place from the 23rd - 25th of October in Madrid. The

Symposium was subdivided into 5 sessions:

1. New insight from OMIC approaches.
2. The cilia centrosome cycle and VHL
3. Diagnosis, prognostic markers and management of VHL.
4. Current therapeutic scenario: From the animal models to the patient.
5. Challenges in surgery of VHL patients.

We like to thank all organizers for this great event. Many presentations can be downloaded of the VHLA:

http://www.vhl.org/wordpress/medical-professionals/international-vhl-medical-symposia/international-vhl-symposium-2014-madrid/

Links

http://www.vhl-europa.org/

https://www.rareconnect.org/en/community/von-hippel-lindau

VHL Europa

Email: board@vhl-europa.org

Website: http://www.vhl-europa.org!