

Powerful Patient 2009, week 34

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Creating Partnership with your Physician

Confronted by a rare disease with little information known about it, Vibeke and Richard Harbud created a support organization, worked with physicians in their country to define a screening protocol, and brought together patients to support each other through the experience. Joyce talks with them about their journey, and about the health care system in Denmark.



1) About our Guests

Vibeke and Richard Harbud live in Denmark. Richard is a technical expert, and Vibeke is a manager in a large European firm. In 1993, with prodding from some of the doctors they were working with, they decided to form a support organization for von Hippel-Lindau. With Richard working on the web, and Vibeke working with the doctors, they formed a strong base of operations which has expanded throughout Denmark, and throughout the Nordic countries: Denmark, Sweden, Norway, Finland, and Iceland.

2) About Partnering with your Healthcare system

In 1993 little was known about how to manage the health of someone with VHL. Problems were treated as they were identified, but waiting for symptoms often means that a problem has already developed to a crucial stage before it is identified.

Working with the doctors in Denmark, Vibeke worked out a screening protocol – a standard set of tests that a patient should undergo on a regular basis, whether or not there were symptoms – in order to try to find issues early, before the symptoms developed. By identifying issues at early stages there would be time to develop a plan of action that would have the best chance of keeping the patient healthy, at work, and in the family.

There was a parallel effort going on from the United States, and both projects benefitted from the other's work. But the experience in Denmark was unique in that the doctors and patient group worked together – within the healthcare system -- to gain consensus on the protocol, work with it for several years, and use their experience to make modifications in the recommendations.

3) The Powerful Patient

In this conversation you will hear Joyce and Vibeke talk about the importance of the patient in this partnership. Even in a healthcare system where the MRI's are free to the patient, and accepted as important by the healthcare system, there are patients who simply do not show up for their appointments. There are emotional factors too that can keep people from complying with what they know intellectually is good advice.

Please refer to our Eight Ways You Can Help Your Doctor Save Your Life.

<http://vhl.org/power/8ways.php>

For more information about von Hippel-Lindau, please see

<http://vhl.org>

For the VHL Handbook, see <http://vhl.org/handbook>

This book is available from Amazon.com.

Members of the VHL Family Alliance (\$25/year) can obtain copies of the Handbook for half price.