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**ERN-LUNG**  
European Reference Network  
for rare respiratory diseases

early diagnosis • best treatment • better quality of life • finding a cure

**PHA EUROPE** *for the patients*

early diagnosis • best treatment • better quality of life • finding a cure

**PH AUSTRIA** *for the patients*



# *Psychosocial Support*

*A Big Challenge*

# *What is important for patients ?*

## Access to medical care system

- PH Center/Hospital
- HCP's
- Diagnosis
- Treatment – various PH-medications
- Rehabilitation
- Care givers
- PH associations
- Psychosocial support



*Psychological Support  
often forgotten*

Consult a psychologist

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Patients

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Relatives

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Care givers

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Friends

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Colleagues

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PH Associations

## *How can PH Associations help*

### PH Associations can be a helping hand

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Keep patients informed and guide them

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Train patients

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Accept the illness

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Increase their self-esteem

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Educate them that they are doing all the efforts for themselves

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Contact to other PH patients

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Confidence to ask their PH doctor all questions

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Social issues

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Teach them to let their body rest and let rest their soul

## *International study*

### *Participation in a pulmonary hypertension support group improves health quality through information and community*

Quelle: <https://journals.sagepub.com/doi/10.1177/20458940211013258?msdynttrid=f1okjW9eDZkdaVg5-1jsUzkYhrYG4mro0MmqYDm4bYg>

88,5 % more confidence  
in selfcare

88,5 % better  
understanding for the  
need of a right heart  
catheterization  
procedure

86,2 % better insight for  
course and symptoms of  
the disease

83,9 % better  
management of their  
symptoms

82,7 % felt more quality  
of life

80,4 % took their  
prescribed medication  
correctly



## *The Work behind the Scenes*

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Networking with doctors, care givers, relatives, study nurses

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Prepare papers

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Be a link with solution providers

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Fight against isolation

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Fundraising

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Awareness

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24/7 hotline

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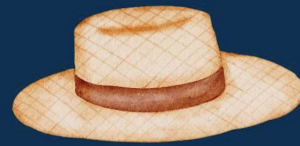
Psychologists and nutritionists in team

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Prof. Franck Rahaghi, MD, Cleveland Clinic Florida

*„HCP’s are treating the patient with the help of drugs from the industry.*

*Pa’s are taking care of the patient in their daily life, which is an important part of the disease management.“*



IT'S INCREDIBLE HOW CONTAGIOUS  
**POSITIVE ENERGY IS.**

-JOHN STRELECKY

Many thanks for your attention