

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

RE-NEWED CALL TO ACTION POSITION PAPER



FOLLOW UP CAMPAIGN WITH
4+(!) MILLION POST
IMPRESSIONS ON SOCIAL MEDIA

CALL TO ACTION

Improve awareness and screening

- Initiate PH awareness campaigns for both professionals and public (including CTEPH)
- Create training programmes on PH for health care professionals
- Create national screening and diagnosis programmes, tailored to PH patient subgroups

Empower patient associations

- Facilitate real-life information exchange between the stakeholders, empower patients to talk about their experiences and treatment about PH and include PH patient associations in debates and decisions which have effect on the lives of PH patients
- Increase the capability of patient associations to serve patients more effectively, particularly through the provision of accurate, evidence-based, regularly updated information and with balanced financial support

Improve access to expert care

- Establish, properly fund and maintain, and integrate high-volume expert centres in local healthcare systems and patients are treated/drugs prescribed/medical interventions are made in such centres
- Establish, regularly review and maintain national and EU policies (also covering special situations) and PH clinical practice guidelines
- Ensure that drugs (combinations thereof), medical interventions (including transplantation with high-prioritised status for eligible PH patients) are available for PH patients without limitations of national policies

Ensure availability of psychosocial support

- Ensure that PH treatment encompasses treatment for the “whole” patient. National systems of integrated care must be instituted, encompassing all aspects of medical, psychosocial, nutritional, and rehabilitative support for patients and their carers
- Afford disabled status to people living with severe forms of PH

Encourage clinical research and innovation

- Ensure more policy, academic support, funding and incentives for:
 - Basic and PH research that leads to effective treatments for all forms of PH and to non-invasive methods for measuring pulmonary pressure and ultimately a cure for PH
 - Capacity of existing centres to support clinical trials and investigational research



HYBRID LAUNCH EVENT
IN THE EUROPEAN PARLIAMENT



CLICK ON THE LOGO
to watch the launch event
Learn more about the initiative at: <http://lnnk.in/bHeZ>

CLICK ON THE IMAGE
to download the position paper