



**Call to Action to Improve
Organ Donation and
Transplantation
across the EU**
PHAEUROPE.ORG

**CALL TO ACTION
to improve Organ Donation and Transplantation across the EU**

INTRODUCTION

Organ transplantation is vital for the treatment and quality of life of patients of all ages - including children - living with a wide variety of conditions, such as the ones affecting the liver, kidneys, heart, lungs, pancreas, small bowel and eyes. In many cases, organ transplantation is the only treatment option remaining - and a matter of survival. This is the case, for example, in pulmonary arterial hypertension (PAH), a rare and life-threatening lung/heart condition.

While the EU is taking a number of positive steps to address this situation - by means of an Action Plan, funding of projects and a Directive on standards of quality and safety of human organs - large differences in practices and results exist across the EU. The demand for organs still exceeds the number of available organs in all EU Member States. Moreover, the demand for organs is increasing faster than organ donation rates.

The Pulmonary Hypertension Association Europe is taking the lead in a campaign to improve organ donation and transplantation across the EU, in cooperation with other patient associations, as this issue is crucial in a number of conditions other than PAH, including many rare ones.

PHA Europe's members, for their part, have committed to promoting this Call to Action and to advocating for better awareness, availability, and access to organ transplantation on a wide scale and mapping the current state of play of the field of heart/lung transplantation in their respective countries.

CALL TO ACTION

PHA Europe calls on the EU Member States:

- to work with and support national patient groups to raise awareness of the vital importance of organ donation and increase the availability of and access to organs;
- to support their national transplant programmes to ensure they reach their full potential for organ donation through more favourable consent systems, improved organisation, coordination, logistics, potential donor reach-out and education;
- to ensure that national transplant programmes take advantage of any technologies which can increase the number of organs available (e.g. organ regeneration);
- to exchange good practices and learnings in order to improve awareness of the importance of organ donation, the urgent and growing need for organs, and increase availability of and access to organs;
- to establish and conclude agreements and cooperate with other countries if the national transplant programmes cannot cover all the domestic needs or if there are no transplant programmes in place.

PHA Europe calls on the European Commission:

- to continue with the implementation of its Action Plan and Directive and ensure extension of these activities beyond the duration of the Action plan, while guaranteeing the participation and involvement of relevant patient organisations;
- to continue to fund projects addressing awareness, availability, access, quality and safety;
- to continue with its implementation surveys to review the impact of the Directive on standards of quality and safety of human organs, Action Plan and funded projects.

PHA Europe calls on the European Parliament:

- to closely monitor the Commission's activities in the field of organ donation and transplantation and request information on the state of play on a regular basis;
- to support stakeholders - patient and health professional organisations - in their efforts to improve both access to transplantation as well as awareness of the importance and benefits to patients;
- to respond to the European Commission's implementation surveys and other activities on the impact of the Directive on standards of quality and safety of human organs, Action Plan and funded projects.

PHA Europe calls on other patient associations and health related stakeholders:

- to support and endorse this Call to Action;
- to join forces in advocating for better awareness, availability, and access to organ transplantation;
- to engage in collaborative work with national authorities, patient associations and health professionals and more widely at European and international level, e.g. within the framework of EU-funded projects.

Vienna, June 1-2015

Endorsements at 15 March 2016:

EUROPEAN ORGANIZATIONS



ESC
Working group on Pulmonary
Circulation & Right
Ventricular Function



ERS
European Respiratory Society



ELF
European Lung Foundation



EURORDIS
European Organization
for Rare Diseases



EPF
European Patients Forum



EPHA
European Public Health
Alliance



EFA
European Federation of
Allergy and Airways Diseases
Patients Associations



ECC
European COPD Coalition



EHN
European Heart Network



ELPA
European Liver Patient
Association



EKHA
European Kidney Health
Alliance



EKPF
European Kidney Patients'
Federation

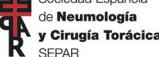


CFE
Cystic Fibrosis Europe

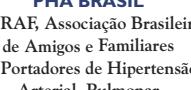
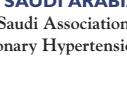


FEDERG
Federation of European
patient groups affected
by Renal Genetic diseases

NATIONAL ORGANIZATIONS

 <p>BOHEMSA Bosnia and Herzegovina Medical Student Association</p>	 <p>OTKUCAJI Civil Society Monitoring of the national health care system in Bosnia and Herzegovina</p>	 <p>BBDB Bulgarian Society of Lung diseases</p>	 <p>BGDONOR Bulgarian National Campaign for organ donation awareness</p>	 <p>IAT Executive Agency of Transplantation Ministry of Health Care, Bulgaria</p>	 <p>NPO National Patient's Organization Bulgaria</p>
 <p>LTPSAS Latvian Society of Lung Physicians</p>	 <p>LKB Latvian Society of Cardiology</p>	 <p>CF Cystic Fibrosis Latvia</p>	 <p>LRSA Latvian Rare Disease Alliance</p>	 <p>LARA Latvian Association for Anesthesiologists and Rheumatologists</p>	 <p>STIFTELSEN Norwegian Organ Donation Association</p>
 <p>SPC Portuguese Society for Cardiology</p>	 <p>SPT Portuguese Transplant Society</p>	 <p>FPC Portuguese Foundation for Cardiology</p>	 <p>ACREDITAR Portuguese Cancer Society</p>	 <p>CHUC University Hospital of Coimbra, Portugal</p>	
 <p>SPFS Slovak Pneumological and Phthisiological Society</p>	 <p>ADTPS The Association of Dialyzed and Transplanted Patients Slovakia</p>	 <p>DAR ŽIVOTA Gift of Life Association, Slovakia</p>	 <p>ŠANKA PRE PEČEN Chance for liver, Slovakia</p>	 <p>OZTP Liver transplant, Slovakia</p>	 <p>STS Slovak Society of Transplant</p>
 <p>NTO Národná transplantácia organizácia</p>	 <p>FENAER Federación Nacional de Asociaciones de Enfermedades Respiratorias</p>	 <p>AELAM Spanish Association for Lymphangioleiomyomatosis</p>	 <p>PULMÓN MADRID TX Madrid Association for Lung Transplant recipients</p>	 <p>SEPAR Spanish Society for Pulmonology and Thoracic Surgery</p>	 <p>AOPC Catalan Transplant Society</p>
 <p>ESC Spanish Society for Cardiology</p>	 <p>ONT Organización Nacional de Trasplantes</p>	 <p>Riksförbundet HjärtLung Swedish Heart and Lung Association</p>			

INTERNATIONAL PULMONARY HYPERTENSION ASSOCIATIONS

 <p>PHA EUROPE European Pulmonary Hypertension Association</p>	 <p>PHA USA Pulmonary Hypertension Association</p>	 <p>PHA JAPAN Pulmonary Hypertension Association of Japan</p>	 <p>PHA LATIN AMERICA Sociedad Latina de Hipertensión Pulmonar</p>	 <p>PHA NEW ZEALAND NZPAH, New Zealand Pulmonary Arterial Hypertension Group</p>
 <p>PHA VENEZUELA FUNDAVHIP, Fundación Venezolana de Hipertensión Pulmonar</p>	 <p>ABRAF ABRAF, Associação Brasileira de Amigos e Familiares de Portadores de Hipertensão Arterial Pulmonar</p>	 <p>HIPUA HIPUA, Hipertensión Pulmonar Argentina</p>	 <p>SAPH SAPH Saudi Association for Pulmonary Hypertension</p>	
 <p>PHASE Saudi Association for Pulmonary Hypertension</p>	 <p>PHABRA PHABRA, Asociación Brasileña de Hipertensión Pulmonar</p>	 <p>PHAA PHAA, Asociación Argentina de Hipertensión Pulmonar</p>	 <p>PHAP PHAP, Asociación Paraguaya de Hipertensión Pulmonar</p>	

PHA EUROPE MEMBERS



AUSTRIA

Selbsthilfegruppe
Lungenhochdruck



BELARUS

Aid to Patients with
Pulmonary Hypertension



BELGIUM

HTAP Belgique, Asbl



BELGIUM

HTAP Belgique, Asbl



BOSNIA AND HERZEGOVINA

Udrženje građana oboljelih od
plućne hipertenzije "DAH" –
u Bosni i Hercegovini



BULGARIA

Pulmonary Hypertension
Association



BULGARIA

The Bulgarian Society of
Patients with Pulmonary
Hypertension - BSSPH



CROATIA

Plava krila - Udruga
pacijenata oboljelih
od plućne hipertenzije



CZECH REPUBLIC

Sdružení Pacientů s Plicní
Hypertenzí



DENMARK

PAH Patientforeningen



FINLAND

Suomen PAH-potilasyhdistys
ry. PHA Finland



FRANCE

HTAP France



GERMANY

pulmonale hypertonie e.v.



GREECE

Hellenic PH



HUNGARY

Tüdőr Egylet



IRELAND

PHA Ireland



ISRAEL

PHA Israel



ITALY

Associazione Ipertensione
Polmonare Italiana Onlus



ITALY

Associazione Malati di
Ipertensione Polmonare Onlus



LATVIA

PHA Latvia



LITUANIA

Žmonių Sergančių Plautine
Hipertenzija Asociacija



NETHERLANDS

Stichting PHA Nederland



NORWAY

PHA Norway



POLAND

Polskie Stowarzyszenie Osób z Nadciśnieniem Plucnym i Ich Przyjaciół



PORTUGAL

Associação Portuguesa
de Hipertensão Pulmonar



REPUBLIC OF MACEDONIA

APH Moment



ROMANIA

Association of Pulmonary
Hypertension Patients



RUSSIA

Natasha Charity Fund



SERBIA

PHA Serbia



SLOVAKIA

Združenie pacientov s plučnou
hypertenziou, o.z.



SLOVENIA

Društvo Za Pljučno
Hipertenzijo Slovenije



SPAIN

Asociación Nacional
de Hipertensión Pulmonar



SPAIN

FNHP Fundación Contra
la Hipertensión Pulmonar



SWEDEN

Nätverket för PAH



SWITZERLAND

Association
HTAP Revivre



SWITZERLAND

Schweizer PH-Verein



TURKEY

Pulmoner Hipertansiyon
Dernegi



UKRAINE

PH URDA - Pulmonary
Hypertension Ukrainian
Rare Disease Association



UKRAINE

Ukraine Association
of Patients with Pulmonary
Hypertension