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