



## **Call to action to improve organ donation and transplantation across the EU - Campaign description**

### **Background**

Organ transplantation (OT) 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.

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 (PHA Europe) is taking the lead in a cross-condition 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.

### **Organ Donation in Europe**

OT benefits about 28.000 patients in the European Union (EU) yearly but the availability of organs does not meet the needs. According to Council of Europe data, by the end of 2014, more than 70.000 patients were waiting for a kidney, liver, heart, lung, pancreas or intestinal transplant in the EU and, each day, on average, 12 people died while waiting for a transplant.

The problem of the availability of organs is a very complex and sensitive one which does not depend on any one single factor but results from a combination of: type of consent systems, organization and performance of national transplant programs and teams, awareness and understanding of the issues in the general population, capacity to engage potential donors, etc.. There can also be ethical concerns (e.g. rejection of brain death criteria) and issues related to cultural and religious beliefs. Even the level of trust in the national health institutions is known to affect decisions of potential donors. Finally, and very importantly, emotions and distress are factors which have to be taken into consideration: most often the decision to donate organs comes at a tragic moment for family members, as they are facing the news of their loved one's passing. Family refusal rates vary greatly across Europe but are quite high in some countries, e.g. over 40% in the UK and France.

There is therefore no easy or ready solution and the problem has to be addressed from many different angles. This is why only a mobilisation of all or as many of the all the players involved is needed for real changes to take place.

### **Need for concerted action of relevant stakeholders**

The Call to Action has already been endorsed by a number of prestigious European and national organizations including the European Respiratory Society (ERS), the European Lung Foundation (ELF), the European Society of Cardiology (ESC) Working group on Pulmonary Circulation, the European Organization for Rare Diseases (EURORDIS), the European Patients Forum (EPF), the European Public Health Alliance (EPA), the European Kidney Health Alliance (EKHA), the European Federation for Rare Renal diseases (FEDERG). We will be reaching out to other relevant stakeholders to ensure the campaign has the broadest base possible.

### **Official launch and activities**

The Call for Action will be officially launched on the European Organ Donation Day (EODD) on October 10 and a number of awareness and advocacy activities are planned around this date and in future months.