PBC Foundation is a nationwide charity based in Edinburgh, which provides help, support and information to sufferers of PBC (Primary Biliary Cholangitis), a progressive autoimmune liver disease with no known cause or cure and which in some cases, can lead to the need for a liver transplant.

90% of PBC sufferers are women, the majority of sufferers between the ages of 40-60. PBC accounted for 7% of all liver transplants in adults in the UK from 1st April 2014 – 31st March 2015, according to NHS Blood and Transplant.

It is estimated that around 20,000 people in the UK have PBC and we have over 900 users of our patient support service in Scotland. We are widely regarded and highly respected as the patient voice of PBC in the UK and our approach is cited by leading specialists in the field of hepatology as a model for patient support.

Do we support the Bill?

The PBC Foundation supports the bill. Having contributed to the consultation with NHSBT (NHS Blood and Transplant) on the system for the allocation and distribution of organs and through our advice to the LPTC (Liver Patients’ Transplant Consortium); we have a strong awareness of the issue of insufficient organs currently available for transplant. Whilst we still await the results of Wales’ recent move to an opt-out system, we are absolutely sure that education must go hand-in-hand with any change in the law.

Public perception needs to be addressed if any change is to be a successful. The PBC Foundation does believe that a change in law could facilitate much greater availability of donated organs, but the degree of improvement is very much subject to the level of awareness and education afforded to the Scottish people.

Would enacting the Bill achieve the aim of increasing the number of organs and tissues made available for transplantation in Scotland?

We, as a nation, have the technology, the expertise, the financial means and the willingness to save far more lives on an annual basis than we currently do. Ideally, there would be an abundance of quality organs from which to select, thereby maximising the life expectancy of everybody that needs an organ transplant. This bill has the potential to make great strides towards those goals. We have the opportunity to change the scope of organ donation and transplantation in Scotland so we need to get this absolutely right. We need to make the protocols simple and timely. We need to make a difficult situation as easy as practicable for grieving family and friends. We need to support the AIPs (Authorised Investigating Persons) and those in the surgical units who are trying to carry out a task in often the most upsetting and emotional circumstances.
Do we support the proposal of appointing a proxy?

PBC Foundation does not support the idea of a proxy. We believe that many quality organs in Scotland are not removed even when prior consent has been given by their owner and they may have even noted it in their will. However, often due to the circumstances and understandable shock and grief of family members at the time of being asked, permission is not given.

In law, a final will and testament will stand even if family members do not necessarily like the decisions carried within. There is very little, if any at all, room for family members at a difficult and traumatic moment to change the decisions within the will. We believe that this should be the same for organ donation. If someone decides to give their organs, it would be morally wrong to allow their family to reverse that decision. We need to be more humane than to expect any proxy to confirm or refute the deceased’s wishes re organ donation.

This leads us to believe that proxy allows an abuse of this system that could lead to too many people’s decisions being reversed without their consent after death. Through our work with the UK-wide LTG (Liver Transplant Group) and LAG (Liver Action Group), we are all too aware of how many times this situation arises. Add to that, any difficulties in locating a proxy and we start to add to the ischemic time-lags pre-transplant.

Thoughts on “authorised investigating persons”

With regards to the AIP, as proposed in the bill, this is not an easy role and must be helped by simplicity of protocols wherever possible. When dealing with organ transplantation, ischemia plays an important role in how successful many grafts are: for all the implications change from organ to organ. Ideally, the AIP would be someone attached to a hospital with open access to records and not impinged upon by understandably emotional relatives.

If the Committee would like clarification of any of the above points or on any other information on the work of PBC Foundation, we would be most happy to assist.