

NORTHERN IRELAND KIDNEY PATIENTS' ASSOCIATION

EVIDENCE TO THE HSSPS COMMITTEE ON THE HUMAN TRANSPLANTATION BILL

INTRODUCTION

- 1 The NORTHERN IRELAND KIDNEY PATIENTS' ASSOCIATION (NIKPA) is a Charity which aims to provide support, promotion and a voice for kidney dialysis patients and kidney transplanted patients and their families.
- 2 It is run by dialysis patients and kidney transplanted patients, their families and friends and is entirely voluntary.
- 3 NIKPA currently have 430 members from around Northern Ireland covering the 7 dialysis units of Northern Ireland
- 4 A primary objective of NIKPA stated in its constitution is the promotion of organ donation
- 5 NIKPA therefore fully support the "SOFT OPT OUT " system as we believe it could be a catalyst for an increase in Organ Donation Rates. However, we have recommendations/concerns.

RECOMMENDATIONS/CONCERNS

- 6 Making family, friends and loved ones aware of your wishes with regard to your decision on Organ Donation is vital. We would therefore urge a comprehensive Education and Public Awareness campaign utilising the personal experiences of transplant recipient and donor family advocates.
- 7 The age for opt out should be 16 years old
- 8 Clause 4 altered to "Unless an objection can be recorded" to clarify decision making in a sensitive situation

WILLIAM JOHNSTON

CHAIR NIKPA

4TH DECEMBER 2015