

Preface

This book has evolved as part of the 2000 Living Donor Consensus Conference, which recommended that all transplant centers have a living donor advocate “whose only focus is on the best interest of the donor.” In 2007, the Department of Health and Human Services (DHHS) and the United Network for Organ Sharing (UNOS) included in their requirements that all transplant centers provide living donors with an advocate. I was appointed to be the independent living donor advocate (ILDA) at our transplant center and since that time have been interested in the development of guidelines to facilitate the best practices of ILDAs to decrease potential harm and bias to living donors and transplant candidates. This book was intended to provide ILDAs with information that would facilitate their understanding of the complexity of the living donor surgeries and medical contraindications, evaluation of the donor by the ILDA, and bioethics involved in living donation. However, the book may also be beneficial to other health care professionals, within as well as outside of transplant, and to potential transplant candidates and living donors.

The first section of the book includes chapters describing the five different types of living donor surgeries that are performed at this time—kidney, liver, intestine, lung, and pancreas—and the medical evaluation and contraindications for such surgeries. A chapter in this section is also devoted to the living donor kidney exchange program, which describes the complexities and nuances of those who participate in these exchanges. The authors who contributed each of these chapters are internationally recognized leaders in their field and graciously shared their time and expertise to provide an overview of these complex surgeries.

The next section of the book is devoted to issues regarding living donor advocacy, and these chapters are written by those who practice as ILDAs or who have donated an organ to a loved one. Many of the ILDAs who have written chapters for this section of the book also serve as leaders in their respective fields and are active in transplant organizations that are advancing the field of transplantation but also involved in the protection of living donors. The first chapter provides a history of living donation and specifically how the role of the ILDA has evolved. This is followed by a presentation of the findings of a national survey regarding the qualifications, practices, and ethical challenges faced by ILDAs. The next chapter describes the advantages and disadvantages of the independent living donor team versus an

ILDA. A subsequent chapter is dedicated to describing the different types of donors. This is followed by a chapter devoted specifically to unrelated donors, who are increasing in numbers at many centers. We have also included chapters describing the timing and components of the ILDA evaluation and contraindications for surgery from the ILDA perspective. This section concludes with a chapter devoted to how disagreements may be resolved between the ILDA and the transplant team, as well as a chapter written by a living donor who shares her experience.

The final section of the book includes chapters about ethical issues related to living donation that are written by ILDA members and others who have expertise in bioethics and are internationally recognized. The first chapter in this section addresses the informed consent process for donors, which is viewed as challenging owing to the Hippocratic Oath, “*primum non nocere*” or “do no harm,” and the frequently unspoken pressures associated with the potential loss of a loved one. The next chapter provides considerations with regard to the assessment by the ILDA of pressure or coercion by the candidate, the candidate’s family, and/or by the medical teams. Valuable consideration and financial risks of living donation are also discussed. A chapter is also devoted to the issue of donor autonomy and the balance between advocacy and protection of donors. A timely chapter on the health disparities that are observed within transplantation and, specifically, living donation is also included. Finally, recommendations for practice guidelines for the ILDA are proposed; however, these recommendations will continue to evolve owing to the constantly changing field of transplant and living donor advocacy.

Living Donor Advocacy

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