Availability of kidney transplantation is limited by an inadequate supply of organs, with no apparent remedy on the immediate horizon and increasing reliance on living donors (LDs). While some have advocated financial remuneration to stimulate donation, the National Organ Transplant Act (NOTA) of 1984 expressly forbids the offer of ‘valuable consideration.’ However, recent developments indicate some fluidity in the definition of valuable consideration while evolving international standards highlight deficiencies (particularly regarding long-term care and follow-up) in the current American system. Recognizing that substantial financial and physical disincentives exist for LDs, we propose a policy change that offers the potential to enhance organ availability as well as address concerns regarding long-term care. Donors assume much greater risk than is widely acknowledged, risk that can be approximated for the purpose of determining appropriate compensation. Our proposal offsets donor risk via a package of specific benefits (life insurance, health insurance and a small amount of cash) to minimize hazard and ensure donor interests are protected after as well as before nephrectomy. It will fund medical follow-up and enable data collection so that long-term risk can be accurately assessed. The proposal should be cost effective with only a small increase in the number of LDs, and the net benefit will become greater if removal of disincentives stimulates even further growth. As importantly, by directly linking compensation to risk, we believe it preserves the essence of kidney donation as a gift, consistent with NOTA and implementable in the United States without altering current legal statutes.

Key words: Incentives, kidney transplant, living donor, public policy

Introduction

Fifty years ago, no effective treatment existed for end-stage renal disease (ESRD). Now, dialysis and transplantation are widely available, and almost all Americans with Stage 5 chronic kidney disease (CKD) are customarily offered renal replacement therapy. Current data indicate that transplantation affords not only better quality of life, but also increases longevity compared to dialysis (1). The prospect of improved outcomes has encouraged more and more CKD patients to seek transplantation (2). However, now that transplants work most of the time, we lack kidneys for the majority of candidates (3).

In an ideal world, increased demand would have been met by an increase in the number of donors. This has not occurred; the gap between demand and supply of deceased donor (DD) kidneys has widened, and, while absolute growth in the number of living donors (LDs) appears dramatic, it in reality reflects only growth in need (Figure 1). In 2005 fewer than 15% of the 70,000 Americans seeking transplants obtained them (3). It is estimated that by 2010, the waiting list will contain over 100,000 names, with many more acceptable candidates never referred (4,5). Despite ample evidence that transplants are most beneficial when performed early in the course of CKD therapy, waiting times, already 5–10 years in some parts of the country, are lengthening, a development that ensures the morbidities that accumulate during chronic dialysis will be amply expressed in those ultimately receiving transplants (3,6). An even more ominous comparison is of annual death rates on the waiting list that over 4 years have increased by 23% (from 6.3% to 8.2%) (7,8). Although, recent years have witnessed modest increases in the number of DD kidneys, their average age has also steadily increased (because of a reduction in traumatic deaths), raising new issues of organ quality (9). In truth, if all potential DDs in the United States became actual donors, there would still be a substantial organ deficit (3,10). While the kidney shortage in the United States is not a novel issue, the sheer magnitude...
The present situation is already generating responses that are similar to those observed with severe shortages in other sectors of the economy. There is an increased willingness to use kidneys whose features may be less than ideal (expanded criteria donors); desperate individuals make public solicitations for directed donations; and some now attempt to go outside the controlled national system to obtain organs from questionable sources (9). At the same time, given increasing reliance on LDs, our responsibility to accurately inform them of and protect them from risk as much as possible is growing; proceedings from a recent international conference regarding care of the live donor highlights those responsibilities and defines potential deficiencies in the current American system, particularly regarding long-term follow-up (11–13). Calls for greater government regulation are increasing (14).

Against this backdrop, our group (the authors, composed of individuals from differing backgrounds—economics, law, medicine and philosophy) came together of our own accord to discuss new approaches that might increase the number of live kidney donors, with a particular focus on the role financial incentives might play as part of a practical, rather than theoretical, solution. Our effort grew out of mutual frustration with the growing organ shortage and observation that years of discussion had failed to generate broad-based action. The authors hold widely divergent opinions regarding the propriety of market-based approaches to increase organ availability. However, we quickly agreed that the current U.S. system, based on presumptions of pure altruism, fails to fully reckon the risks (financial and physical) assumed by LDs, and makes no provision to compensate for those risks. Though we, as other interested parties, continue to disagree as to the ideal approach, the proposal presented herein establishes a middle ground between those of us who favor market mechanisms (chiefly payment) (15,16) and those who maintain that payment for organs raises significant ethical concerns and may ultimately stifle the positive altruistic attributes underlying current policy (17–19). Until now, the restriction against provision of ‘valuable consideration’ codified in the National Organ Transplant Act of 1984, P.L. 58-507 (NOTA, Table 1) has been interpreted as precluding most any form of donor compensation. However, we believe the key components of our proposal are not only consistent with NOTA, but are a necessary step in U.S. implementation of evolving worldwide standards regarding LDs and recent recommendations of the Amsterdam Forum on Care of the Live Donor (12).

### Eliminating the Organ Shortage

There are only two ways to eliminate the organ shortage. The first is to reduce demand. Criteria for transplantation could be made restrictive enough that similar numbers of patients are listed and transplanted each year. Defining stricter limits would, however, create numerous ethical issues regarding priority. Some might term such an approach as a ‘straw man’, a change so absurd as to be unworthy of consideration. However, credible proposals are already circulating that would promote allocation of DD kidneys to younger, healthier patients (20). Nowhere else in American

### Table 1: Pertinent passages from Section 301 of National Organ Transplant Act

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<td>(a) It shall be unlawful for any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce.</td>
<td>Any person who violates subsection (a) of this section shall be fined not more than $50,000 or imprisoned not more than 5 years, or both.</td>
<td>For purposes of subsection (a) of this section:</td>
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<tr>
<td>(b)</td>
<td></td>
<td>(1) The term ‘human organ’ means the human (including fetal) kidney, liver, heart, lung, pancreas, bone marrow, cornea, eye, bone and skin or any subpart thereof and any other human organ (or any subpart thereof, including that derived from a fetus) specified by the Secretary of Health and Human Services</td>
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<td>(2) The term ‘valuable consideration’ does not include the reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control and storage of a human organ or the expenses of travel, housing and lost wages incurred by the donor of a human organ in connection with the donation of the organ.</td>
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<td></td>
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<td>(3) The term ‘interstate commerce’ has the meaning prescribed for it by section 321(b) of Title 21.</td>
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Gaston et al.

medicine are health professionals required to make such Faustian decisions, and no precedent exists for their making.

The only other solution is to increase the supply of transplantable kidneys. Accordingly, a recent Institute of Medicine (IOM) report recommends substantially increased efforts to enhance recovery of organs from DDs (18). However, given the limitations noted above, and the near-term unlikelihood of xenografting, we believe the only way to substantially change the dynamic of the current impasse in kidney transplantation is an increase in the number of LDs. Our proposal, which does not address the shortage in transplantable hearts or livers, should be viewed as complementary to, not a substitute for, ongoing efforts (such as the Organ Donation Breakthrough Collaborative) to increase the number of DDs (21).

Economic Benefits of Kidney Transplantation

The financial benefits of a successful kidney transplant are enormous, to both recipient and society. In a recent article, Matas and Schnitzler calculated that a single LD transplant saved taxpayers a minimum of $34,000 over the average lifespan of the allograft compared to the cost of maintenance dialysis (22). This estimate did not include savings associated with reducing the size of and duration of time spent on the waiting list. Nor did it include the impact of improved quality of life in the recipient, which clearly has financial implications as well. In a different context, two economists, Murphy and Topel, estimated that increases in longevity and health since 1970 produced aggregate gains of $2.6 trillion per year, with men at age 50 gaining $350,000 per year in additional satisfaction, and women of that age about $180,000 (23). While one might quarrel with these figures, a quality of life improvement of $50,000 per year per patient (of transplant vs. dialysis) looks to be very conservative, bringing the total economic benefit of an average LD kidney transplant, with anticipated half-life of at least 10 years, to well over $500,000 (24).

Risks of Donor Nephrectomy

The perioperative mortality (0.03%) and morbidity (<2%) associated with kidney donation are well documented (25,26). However, the short- and long-term health and social impacts of donor nephrectomy remain relatively undefined, owing in part to the paucity of long-term follow-up studies, the most comprehensive of which are from Western Europe (27–29). While it is known that some American donors eventually develop CKD themselves, long-term medical risk associated with donor nephrectomy cannot be accurately assessed in this country due to the patchwork access to health care afforded donors at this time (30).

Several studies have documented the impact of nephrectomy on a donor’s subsequent quality of life. Although most donors look back at the event favorably, some do not, especially when perioperative complications occurred or the recipient had a bad clinical outcome (31,32). Financial implications of donor nephrectomy are even less well defined. Hiller and colleagues found 70% of 61 LDs to have expressed socioeconomic concerns before making the decision to donate (33). Of these, 29% worried about financial ramifications of time missed from work, 10% about childcare, 2% about job security and another 2% about future health insurance coverage. Prospective donors who did not ultimately donate reported similar concerns (34). Estimates of out of pocket expenses associated with donation range from $550 to $20,000 (32). Exact quantitation of the number of potential donors ultimately dissuaded from proceeding by financial concerns is not available, although a recent survey indicates it may be as high as 40% (35).

A New Proposal

In order to address the issues outlined above, our group made several assumptions, most of which are evidence based. First, although circumstances have changed over the past half century, risks associated with donor nephrectomy remain ethically justifiable and medically acceptable (26,36). Second, the outcome of LD transplants (patient and graft survival) is better than that of DD transplants; results with allografts from unrelated living donors (LURD) are equivalent to the those attained with related donors (3). Third, under current policy in the United States, donor interests remain unprotected relative to current Western standards: risk cannot be quantitated (particularly among ethnic minorities) and LDs are not adequately shielded from financial and health consequences associated with nephrectomy (12). Fourth, notwithstanding NOTA, there is sustained ethical opposition to the use of an open or unregulated market in LD organs (19). Fifth, recent programs enacted nationally and locally reflect general agreement not to allow financial disincentives to impede donation.

Details of the proposal

We propose LDs be provided an inalienable package of benefits that would not enrich anyone (provide valuable consideration) but rather is designed to leave the donor as well off (fiscally and physically) as before donation. The goal of this proposal is to protect donors from uncompensated risks of death, bodily injury, loss of capacity or financial dislocation, and in so doing, encourage more potential donors to pursue their altruistic impulses (11,17). While we would expand compensation beyond what currently is accepted by many in the field, we also cap the total amount at levels far below what proponents of open markets would prefer. We acknowledge that any package of benefits would increase the overall cost of LD transplants; however, these increased costs are more than offset by savings resulting from decreased utilization of long-term dialysis. The
Figure 2: The debate regarding incentives for kidney donation assumes that a potential donor begins at some neutral level (0) where there is no cost to donation, and that significant financial benefit will be offered to induce an otherwise unwilling person to undergo nephrectomy. The current proposal makes a different assumption, namely that there are substantial costs currently assumed by the altruistic donor, with the net impact of the transaction represented by point (A). The financial (and health) sacrifice (net cost) represented by (A) is the true ‘starting point’, and dissuades many from donating. At this level (A) of net donation costs we realize X donors. The current proposal (represented by line point B) compensates losses only partially, removing a portion of the disincentive, and encouraging donation so that the number of donors increases from X to Y. In accord with NOTA, the donor is not enriched relative to position before nephrectomy, and the basic nature of the transaction (as gift) is preserved.

The rationale underlying our proposal is summarized in Figure 2 (and its legend). Specific details of the proposed donor benefits package, including cost projections, are outlined in Table 2. In our cost estimates, a fixed amount was chosen to avoid the complexity of individualization based on income or family circumstance.

First, to cover the small but real mortality risk, we propose a 1-year term life insurance policy of $1 000 000, to be adjusted for inflation. The choice of that figure is less than the $6 000 000 amount that is often used in the valuation of human lives, but is still substantial and would help any affected family over a serious financial hurdle. This term life insurance would be in addition to already existing private coverage, and its spirit is in keeping with the well-intentioned but poorly subscribed voluntary life insurance benefit currently offered through the Southeastern Organ Procurement Foundation (SEOPF) (37).

Second, to offset any increased risk of medical complications after donation, we propose health insurance for long-term medical care. To avoid duplication, it would be integrated with other forms of coverage already in place for individual donors, and would consist of a supplemental, nontransferable policy to cover any shortfall that might occur. The simplest way to implement this aspect of the package would be to make all donors Medicare eligible from the time of donation (median age: 40 years) until they reach 65 years of age or otherwise qualify (38). This component would ensure that all donors have access to long-term follow-up, making outcomes relatively easy to track even without creation of a new donor registry. The impact of nephrectomy on long-term donor health in this country could at last be reliably determined (11).

Third, we would include reasonable sums to reimburse travel and lost wages associated with time off work, during both the evaluation and perioperative phases. Potential donors incur these expenses deliberately for the benefit of others, and should not be subject to the vagaries of individual employers. This component differs from coverage offered under workers’ compensation and disability programs, which often require waiting periods before compensation is awarded.

Fourth, we recognize that kidney donation involves inconvenience, pain and anxiety that starts before and lasts beyond the operation, as with any significant surgical procedure. We believe that either a tax deduction of $10 000 or a nontaxable lump sum payment of $5000 would be an appropriate offset for this inconvenience. As a group, we could not agree on which of these options is best. In general, we favored a tax deduction, but recognized it would be of no benefit to the significant proportion of the population that does not pay income taxes. As a compromise, we propose both be offered, allowing the donor to decide.

<table>
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<th>Table 2: Proposed benefits and estimated costs</th>
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<td>One-year-term life insurance policy:</td>
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<td>Death benefit equal to $1 000 000</td>
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<tr>
<td>Health insurance:</td>
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<td>Medicare as primary or secondary insurer from donation until age 65 years or otherwise eligible</td>
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<tr>
<td>Reimbursement of out-of-pocket expenses/lost wages related to donor evaluation and/or nephrectomy</td>
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<td>Compensation for inconvenience, anxiety, and/or pain</td>
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<tr>
<td>$5000 cash or $10 000 tax deduction</td>
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<td>Total cost estimate per achieved donor</td>
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Estimated costs and funding of the proposal

The cost (in premiums) of life insurance is fundamentally derived from the actuarial expectation of loss. Perioperative mortality has been estimated at 0.03%. If we assume that an additional 0.1% of donors die because of donation, then the expected cost of the $1 000 000 payment per death would be $1300 per donor. A higher donor-associated death rate of 0.3% would bring the total to $3300 per donor.

Medicare coverage costs can be estimated from the current median donor age (40 years) and the realization that all citizens become eligible for coverage at age 65. Thus on average, 25 years of additional eligibility would be required. Modifying Center for Medicare and Medicaid Services (CMS) estimates of the cost of 30 years of coverage for disabled beneficiaries, one may derive a projected cost of $18,124 per donor (range of $15,000–20,000/donor). Since many donors already have private insurance, and donors represent an extremely healthy segment of the general population, actual costs are likely to be much less (39).

The costs of travel and lost wages can be estimated from reports in the literature. Johnson and colleagues, in a survey of former donors, reported mean personal expenses (travel, lost wages and other costs) of $579. Nonetheless, a wide range of personal expenses was reported ($0–$20,000). At the University of Alabama at Birmingham, 1003 potential donors were evaluated between 2001 and 2004, and 622 LD transplants were performed, indicating that 38% of evaluated donors never proceeded to nephrectomy. These persons also lost wages and costs of travel, and should be included in this part of the compensation package. Thus, the total actual and prospective donor personal costs from these historical studies ranges from $724 to $1449 per achieved donor. If our proposal is implemented, we presume that the availability of compensation for travel and lost wages would lead to an increased pool of potential donors taking time off work and traveling greater distances. Therefore, we triple the historical estimates and assume the average figure for travel, lost wages and personal expenses would range from $2225 to $4500 per achieved donor. Due to disparity across income categories, a fixed sum might be the simplest and most equitable approach to deal with this issue.

Finally, adding a $5000 direct payment (or a $10,000 tax deduction) to these costs for loss of amenities and anxiety produces a range for the cost of our proposal of $23,525–$32,800 per donor. While at first glance expensive, it is far less than—and easily offset by—the estimated $94,000 savings to the health care system generated by the average LD kidney, and approximately half the cost of a single year on dialysis ($58,000) (22,40). Using the midpoint of our range to calculate the financial implications of our proposal indicates that each newly generated donor produces a net financial benefit (to payers and society) of at least $66,000.

Funding sources for this proposal should be readily available via the Medicare ESRD program administered by CMS. To offset costs of the proposal, including making benefits available to currently uncompensated donors, the number of donors must increase proportionately beyond the 6647 individuals who donated kidneys in 2004. For the program to be cost neutral to CMS, an additional 2800 donors per year are required, a 43% increase. Given data that 25–40% of potential donors may be dissuaded by financial concerns (see above), such an increase seems quite plausible. The shift of funds from one modality of kidney treatment to another places no additional burdens on the public treasury, and therefore does not require a separate appropriation. The improved outcomes (including quality of life) for patients in the Medicare ESRD program compellingly support such a proposal.

Some may object to the proposal as offering benefits more attractive to the less affluent than the well-off, with a potential for significant exploitation of poorer Americans. However, the scope of the package we advocate serves only to bring donor compensation in this country in line with current Western standards, with donor care covered under national health insurance in most countries, and insurance against death, disability and financial dislocation in some (37,41,42). It is difficult to view this proposal as materially enriching anyone enough to coerce an otherwise unwarranted decision to donate. Nonetheless, its implementation would require oversight of subsequent impact on different segments of society. A sensible first step might be a pilot project, with resulting information enabling all interested parties to ascertain the overall risks and benefits.

NOTA

Recent developments in LD transplantation (including paired exchange, paid leave and expense reimbursement) reflect the evolving will of the populace and already challenge the strictest interpretation of NOTA. The obvious cases of ‘valuable consideration’ are cash and other benefits which might be offered in a bargain setting as a quid pro quo for the surrender of an organ, a practice almost universally condemned throughout the world (18,42). In the context of the current proposal, such obvious cases would include any payments that left donors above the x-axis in our diagram (Figure 2). But there are some complications to this matter. Organ swaps between donor/recipient pairs in response to tissue incompatibility could be regarded as in-kind exchanges that trigger the criminal sanctions of the statute. On advice from counsel, UNOS has treated these as ‘altruistic’ transactions even though the one transplantation is an evident quid pro quo for the second:

The donation of an organ is properly considered to be a legal gift, rather than a contractual undertaking. By definition, there is no ‘consideration’ at all in a gift transaction. Like all gifts, organ donations may be made for specific purposes. There is no valuable
Even though the 'valuable consideration' language read literally covers this situation, the implicit position of UNOS is the want of any cash payment in either direction takes these swaps out from the basic statutory prohibition. In face of this interpretation it becomes hard to argue for an unfaulingly strict application of the phrase 'valuable consideration.’

In addition, under the definitional section (c) of NOTA, all benefits that are supplied to the donor do not fall under the prohibition, for the term valuable consideration ‘does not include the expenses of travel, housing and lost wages incurred by the donor….’ The ‘Organ Donor Leave Act’ of 1999 authorizes 7–30 days of paid leave for federal employees who donate organs (44). Wisconsin recently enacted legislation authorizing state income tax deduction of up to $10 000 for lost wages and expenses associated with the act of donating an organ. A number of additional states enacted similar legislation, and comparable policies are undergoing evaluation on the federal level (45,46).

Clearly, all benefits that are supplied to the organ donor do not fall under the prohibition, nor are the various heads of payments restricted to those made before transplantation takes place. They apply equally well to all the dislocations that take place after transplantation. Only an artificially narrow reading of the phrase ‘reasonable payments associated with removal’, for example, would ignore the losses that take place in consequence of organ donation. The statutory language contains no restriction that these costs be common to all transplants, but allows any relevant costs, including those incurred by only a small fraction of donors, to be offset. Likewise the phrase ‘in connection with’, does not require any tight or invariant connection between the lost wages and the organ transplant.

Our proposal only contemplates the coverage of lost wages that are fairly incident to the transplantation, even if they occur after it. No profit is to be derived over and above the lost wages and expenses associated with the act of donating an organ. A number of additional states enacted similar legislation, and comparable policies are undergoing evaluation on the federal level (45,46).

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Our proposal only contemplates the coverage of lost wages that are fairly incident to the transplantation, even if they occur after it. No profit is to be derived over and above the costs inherent in donating a kidney, and the intention is to leave persons indifferent, to the extent that various benefits can make them, to giving or retaining an organ. It preserves altruism (in its broadest interpretation) as primary motivation, is simple, and, we think, well within current NOTA and societal standards. Its logic is based on the undeniable selflessness inherent in organ donations, even toward strangers, and recognizes the legitimacy of ethical objections against market-based solutions that might promote profiteering by or exploitation of donors (47). We contend that this proposal does not skirt to the edge of NOTA, but actually embodies the aims and intentions of the statute.

Limiting Financial Disincentives

Final Reflections

Currently, the debate regarding utilization of financial incentives to promote organ donation is highly polarized between advocates and opponents. Proposals ranging from reimbursed expenses to fully unregulated free markets in kidneys have been eloquently debated in philosophical and medical forums (15,16,19,48). In the meantime, we continue to abandon donors into the vagaries of the American healthcare system, largely unaware of what lies ahead in their lives, even as the waiting list grows ever longer. While we recognize the benefits to society at large of dynamic intellectual exchange, our proposal tries to go beyond lamentation and abstract discussion to a workable compromise that promotes the interests of everyone involved.

We in no way wish to minimize the enormous sacrifices of previous live donors. But we think the shift in social circumstances has brought about an increased demand for kidneys—without a commensurate increase in supply—requires exploration of approaches that might have seemed outlandish in 1984 when NOTA was implemented. Well-intentioned attempts to preserve a pure altruism, while noble, fail to recognize the true cost to donors and our responsibility to ensure donor safety, not to mention the scope of unmet needs in desperately ill patients, even as they have all increased over time (17).

As acknowledged in the recent IOM report, new approaches are necessary (18). We believe our proposal to be ethically consistent with the IOM mandate. It would compensate donors for the real costs incurred by their endeavor without exploiting those potential donors whose circumstances might cause them to be blinded by overt financial offers for their organs. Market proponents must recognize the validity of longstanding tradition and current mores: in Western society organ selling within established markets has always been subject to deep aversion, as reflected in NOTA’s sharp restriction on the types of valuable consideration allowed. Organ selling may or may not be ethically defensible, but it is not practical. Market opponents, however, must concede not all financial incentives will invariably corrupt the system; there need be no slippery slope to exploitation and social decay. What principle are we defending by basing solutions to the unconscionable kidney shortage solely on assumptions that an ever greater number of persons will continue to accept uncompensated risk of bodily harm or financial disruption?

The authors understand this proposal, by staking middle ground, may be alienated from natural constituencies on both sides of the organ markets debate. Nonetheless, we believe compensating donor risk in the fashion we propose, or something akin to it, is not only an acceptable alternative to the current impasse, but also the right thing to do. We hope that from the controversy this paper...
generates will emerge open consideration, then further refinement, and, ultimately, implementation of policy change of potentially great benefit to patients and society.

Acknowledgment

The authors wish to thank Ms. Wendy Bailey of UAB for her efforts facilitating this project.

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