



## ***PKD Foundation Advocacy Champions Network Guide to Writing a Policy-Focused Patient Advocate Letter-to-the-Editor (LTE)***

***In this phase of the Advocacy Champions Network, we're working with ACN Members to publish custom LTEs in your local newspapers across the country. We'll follow these steps:***

1. Champions will write the first LTE draft (see step-by-step guidance below) and send to Sydney for review: [sydney.shepherd@curastrategies.com](mailto:sydney.shepherd@curastrategies.com)
2. Sydney and the CURA team will work with each Champion to prepare a final draft ready for publication
3. Champions will then submit the LTE to a local publication
4. Once published, the LTE can be promoted by the PKD Foundation and flagged for your Federal representatives

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### **The PKD LTE Checklist**

*Each letter will have these features and follow this general flow:*

- ✓ Here is an [example LTE about the LDPA](#). It balances personal words with statistics to get the message across
- ✓ Around 250 words in length
- ✓ One topic that is important to you and your experiences with PKD advocacy. Since space is limited, it's important for your piece to have a specific focus and tell one story. Some topic examples: kidney donation/transplantation, need for more provider awareness or funding for researchers, health disparities in treatment, gaps in insurance coverage, the need to incentivize living donation, etc.
- ✓ Statistics that back up your persuasive argument or personal story, showing that your issue is not isolated and relates to a broader problem
- ✓ A call-to-action in your conclusion that the reader can act on or support, in this case, getting involved with your local PKD community or supporting the PKD Foundation's legislative priorities

### **Recommended Focus: Living Donor Protection Act**

#### ***Key Statistics and Facts:***

##### *Kidney Donation and Transplantation:*

- Living donors make up a vital portion of the kidney transplants performed in the U.S. each year. About 25% of the kidney transplants in 2022 were living donations.
- However, 25% of living donors are denied or charged more for life insurance.



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- There are nearly 100,000 individuals on the kidney transplant waiting list; however, just 20,090 transplants were performed in 2022.
- Each day, 17 people die waiting for an organ transplant. 12 of those who died were waiting for a kidney.

*Living Donor Protection Act:*

- Currently, there is no federal legislation protecting living organ donors from losing their jobs to take time off to recover from transplant surgery. Living donors may experience higher premiums or denial of coverage for life, disability and long-term care insurance.
- The LDPA prohibits discrimination in insurance practices based on an individual's status as a living organ donor. This includes the offering, issuance, cancellation, breadth of coverage, price, and any other condition of a life insurance policy, disability-insurance policy, or long-term-care insurance policy.
- Additionally, the LDPA federally designates recovery from organ-donation surgery as a serious health condition. This entitles covered private-sector and federal employees to much-needed medical leave. With the passage of this legislation, living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from their gift of donation.
- The LDPA also requires the Department of Health and Human Services (HHS) to conduct public awareness campaigns that educate Americans on the benefits of living organ donation and these changes in insurance that would arise from this new law. Additionally, this campaign will ensure existing donors are aware of their rights to access the necessary insurance without fear of exorbitant premiums or denied coverage.

**Template LTE\***

*\*This is just an example to help guide your writing process. Please personalize and add in any state-specifics to make the LTE most relevant to your community*

*As someone [living with Polycystic Kidney Disease (PKD)/ on the transplant waitlist/ living with a transplanted kidney], I am deeply aware of the urgent need for more living organ donors. To help make this possible, I urge policymakers to champion the Federal Living Donor Protection Act (**BILL NUMBER**), a vital lifeline for both transplant patients and living organ donors.*

*Living donors play a critical role in kidney transplants and deserve our utmost support, yet they often face barriers, such as insurance discrimination or the inability to take time off work to recover from surgery. For example, 25% of living donors are denied coverage or charged higher premiums for life, disability, and long-term care insurance.*

*The LDPA aims to rectify this injustice by prohibiting insurance practices that discriminate against living organ donors and providing the appropriate medical leave for surgery recovery. It*



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*safeguards a living donor's financial stability and job security to encourage more people to selflessly come forward as donors, ultimately saving lives.*

*While the bill has received significant bi-partisan support and there has been progress in passing similar legislation in the states, the federal bill has failed to pass for almost 10 years.*

*[Share more about your story and what living donation means to you] OR: With nearly 100,000 individuals on the kidney transplant waitlist and 17 people dying each day while waiting for an organ transplant, the need for action is undeniable. By backing the LDPA, we can increase living organ donations, alleviate the burden on the waitlist, and give hope to countless families.*

*Together, with leading advocacy organizations like the PKD Foundation, we can finally give living organ donors the protections they deserve. Visit [XXXXXX](#) to learn more.*