



PKD FOUNDATION  
**ADVOCACY CHAMPIONS  
NETWORK**

# **August Recess: Engaging Lawmakers and News Outlets in the District**

July 19, 2023



**PKD FOUNDATION**  
Polycystic Kidney Disease

# Legislative Update

## Living Donor Protection Act

- Joint Committee on Taxation said the bill would increase revenues by **less than \$1M over 10 years.**
- They anticipate that the bill would lead to a small uptake in use of FMLA. However, because the FMLA portion is codifying existing DoL guidance, the revenue score could also be 0.

## CDMRP PRMRP

- **Senate report language has not been released**

## The Organ Transplantation Transparency, Accessibility, and Reform Act (OTTAR)

- **Currently being reviewed by HHS**



# LDPA cosponsors who met with advocates during PKDF's VAD 2023

## House of Representatives (22)

- ▶ Rep. Adriano Espalliat (D-NY-14)
- ▶ Rep. Ann Kuster (D-NH-2)
- ▶ Rep. Betty McCollum (D-MN-4)
- ▶ Rep. Bradley Schneider (D-IL-10)
- ▶ Rep. Chris Deluzio (D-PA-17)
- ▶ Rep. David Scott (D-GA-13)
- ▶ Rep. Don Davis (D-NC-1)
- ▶ Rep. Dutch Ruppersberger (D-MD-2)
- ▶ Rep. Gerald Connolly (D-VA-11)
- ▶ Rep. Gus Bilirakis (R-FL-12)
- ▶ Rep. Hillary Scholten (D-MI-3)
- ▶ Rep. Jamie Raskin (D-MD-8)
- ▶ Rep. Jeff Van Drew (R-NJ-2)
- ▶ Rep. Jaoquin Castro (D-TX-20)
- ▶ Rep. Joseph Morelle (D-NY-25)
- ▶ Rep. Josh Harder (D-CA-9)
- ▶ Rep. Joyce Beatty (D-OH-3)
- ▶ Rep. Lisa Blunt Rochester (D-DE-AL)
- ▶ Rep. Madeline Dean (D-PA-4)
- ▶ Rep. Scott Peters (D-CA-50)
- ▶ Rep. Ted Lieu (D-CA-36)
- ▶ Rep. Thomas Kean (R-NJ-7)

## Senate (13)

- Sen. Ben Cardin (D-MD)
- Sen. Bob Casey (D-PA)
- Sen. Cory Booker (D-NJ)
- Sen. Ed Markey (D-MA)
- Sen. Gary Peters (D-MI)
- Sen. Jon Ossoff (D-GA)
- Sen. Kirsten Gillibrand (D-NY)\*
- Sen. Kyrsten Sinema (I-AZ)
- Sen. Marco Rubio (R-FL)
- Sen. Mike Braun (R-IN)
- Sen. Raphael Warnock (D-GA)
- Sen. Thomas Tillis (D-NC)
- Sen. Todd Young (R-IN)



# A Look at the Next 6 Weeks

## IN-DISTRICT MEETINGS AND LTE PITCHES

1

Draft an LTE for Placement In Local News

Interested Champions will begin pitching letters to the editor (LTEs) to local news outlets to raise awareness for the LDPA and/or other PKD related issues

2

Schedule an In-District Meeting

Interested Champions will work to secure meetings with their federal lawmakers while they are in the district.

Reference your outreach toolkit for more information!



CONGRESSIONAL OUTREACH TOOLKIT

### Pre-Meeting Checklist

- o Identify if there are any other ACN members from your congressional district. If there are, be sure to coordinate your outreach as a group – determine who will contact the health staffer to set up your meeting with your Representative. If you are the only one from your district, please proceed with outreach on your own.
- o Reference the contact list below to identify the health staff contact in your House Representative's office. We have included an email template below to inform your outreach emails. **Plan to have your first outreach email sent by Wednesday, August 18.** If you don't hear back from your contact within five business days, send a brief follow-up message
- o When your contact responds and you've confirmed the time and date of your meeting, email [pkd.meetings@curastrategies.com](mailto:pkd.meetings@curastrategies.com) with the below information:
  - Name
  - House office
  - House staffer
  - Time/Date of Meeting
- o Review the appropriate briefing materials to ensure you are prepared to discuss PKD and the Living Donor Protection Act (H.R. 1255) with your member.

### Meeting Checklist

- o Have a copy of your talking points or [the LDPA one-pager](#) handy to reference throughout the conversation—highlight or make note of any important points you



# What is a Letter-to-the-Editor? (LTE)



**SHORT AND CONCISE.** Typically 250 words or less.



Sometimes written in direct response to an article or op-ed in a publication.



Fast publishing turnaround time.



Perfect way to respond to the issues of the day and publish your views.



# What are the key elements of writing and submitting an LTE?

- Follow LTE submission requirements **PERFECTLY**. They will not publish your work if you don't meet their criteria
  - Look for: length, submitting instructions and requirements related to formatting, disclosures, and contact information
- Use a timely hook and illustrate the human impact with a few supporting data points
- Be sure to include any local connections you have to the community (either as a part of the piece, or in your submission information)
- If sending to an editor via email, it's best to paste your LTE in the body of an email—do not attach

## NEW HAVEN REGISTER

OPINION

Letter to the Editor: Help protect living donors

May 27, 2016



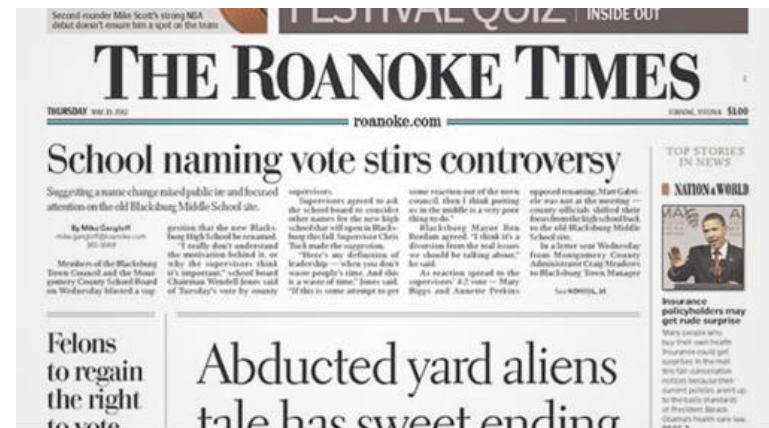
letters  
Journal Register Co.

Many living organ donors today experience higher premiums or denial of insurance coverage based solely on their status as a donor. But hopefully not for long. In late February, the Living Donor Protection Act was introduced in the [U.S. Senate](#) and in the [House of Representatives](#). This bill will protect living organ donors by prohibiting insurance companies from denying or limiting life, disability and long term care insurance to living donors, and from charging higher premiums. The bill also clarifies that living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from donation.

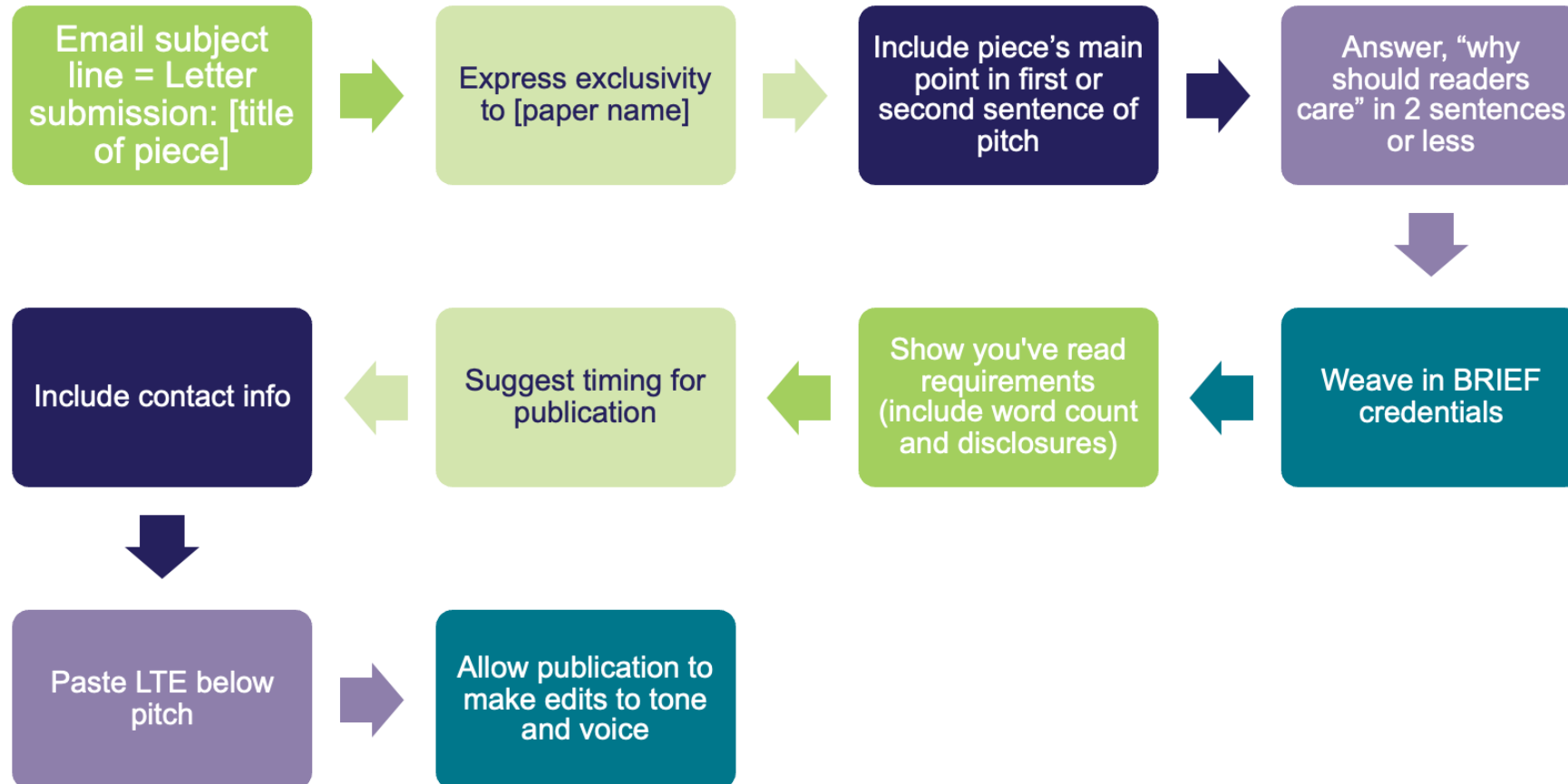


# How do you select the best outlet?

- Conduct a quick Google search to determine which newspapers in your area have the highest readership
  - Readership can also be referred to as circulation or website visits. If you don't live in a metropolitan area, consider newspapers that are headquartered in the closest city to you, or the state capitol
- Once you've determined which outlet you'd like to submit to, search their website for letter-to-the-editor submission guidelines (this could be included in their opinion section, also referred to as viewpoints or perspectives)



# What is the typical process for submitting?





# Next Steps

Next week, CURA will send you an LTE drafting guide

You will make it your own—as you feel comfortable—with an eye toward publishing it in a local outlet

CURA will review and provide any feedback before you send to your local outlet with a request for your piece to be published

The Foundation will amplify this coverage and ensure that your story is properly broadcast across PKDF channels and to your Federal reps



# In-District Meetings

- Determine which lawmaker you want to meet with and contact your Member's office to schedule in person or virtual meetings **no later than Wednesday, August 9**
- **Meeting Agenda:**
  - Introductions
  - What is PKD?
  - The Living Donor Protection Act
  - Questions?
- **Don't forget to follow up!!**

*Reminder: Notify CURA staff when your meeting has been secured so that we can participate virtually if applicable.*



# LDPA: FAST FACTS

**What are the bill Numbers?** S.1384/H.R. 2923

**Who are the Lead Sponsors/Original Cosponsors?** Representatives Jerrold Nadler (D-NY), Troy Balderson (R-OH), Lisa Blunt Rochester (D-DE), Congressman Jim Costa (D-CA), Congressman John Curtis (R-UT), Diana DeGette (D-CO), Congresswoman Mariannette Miller-Meeks (R-IA), Congressman Gregory F. Murphy, M.D. (R-NC), and Senators Kirsten Gillibrand (D-NY) and Tom Cotton (R-AR).

**Has this bill received Technical Assistance (TA) or been scored?** The bill has received technical assistance (TA) from the Department of Health and Human Services (HHS) and the Joint Committee on Taxation scored the bill at less than \$1 million over 10 years.

**Who else supports LDPA? Do any organizations oppose it?** LDPA has broad support from other health care organizations and life insurance groups including the National Kidney Foundation, the American Kidney Fund, the American Society of Transplantation, the American Society of Nephrology, and the American Council of Life Insurers

**Has the bill been introduced in previous Congresses? If, so what have been issues in getting the bill passed.** Yes, the bill was introduced in the 113<sup>th</sup> – 117<sup>th</sup> Congresses. In previous years, the insurance industry was quietly working against it, but those issues have been resolved and many insurance groups are now onboard and supportive of the bill.



# UPCOMING EVENTS & IMPORTANT DATES

- Upcoming Webinars:
  - Tuesday, August 15 (8pm ET/5pm PT): Racial Disparities Legislation *\*\*\*Tentative*
- LDPA Action Alert– Complete if you haven't and encourage others to join us!
- MightyNetwork as an online community – More coming soon!



# QUESTIONS?



# Contact Us



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