



# Rare Kidneys on the Hill Day 2023

Know Before You Go Webinar

<https://resources.nephcure.org/hillday2023>

# Let's get to know one another.

## Type in the chat...



### Name

Britta Dornan,  
NephCure Executive  
Director, Strategic  
Relations



### City/State

Moved to Billings,  
Montana last year



### Why are you an advocate?

My sister and I are rare  
disease patients



### Are you a first time or returning advocate?

Returning but first for  
NephCure. Multiple  
Lymphedema Treatment  
Act and EveryLife  
Foundation for Rare  
Diseases Hill Days  
previously.

# Webinar Agenda

## **Rare Kidneys on the Hill Day Schedule and Logistics**

Britta Dornan, NephCure Executive Director, Strategic Partnerships

## **Civics Refresh, Washington Update & 2023 Rare Kidneys on the Hill Day Suggested Policy Asks**

Phil Goglas and Matt Duquette, Health and Medicine Counsel, LLC

## **Making the Most of Your Capitol Hill Meetings and Connecting Your Story to Policy Asks**

Mary Baliker, patient and healthcare consultant

## **Making an Impact on Hill Day 2023: Social Media Advocacy Training**

Nick Garlow, Rational 360

## **Question & Answer**

# Schedule and Logistics

**Britta Dornan**

**NephCure Executive Director, Strategic Relations**

**Tuesday, July 11<sup>th</sup>**

**Location:**

The Grand Hyatt  
1000 H Street, N.W.  
Washington, D.C.  
(202) 582-1234

**4:00 p.m. – 6:00 p.m.**

Arrival and Registration

**6:00–9:00 p.m.**

Rare Kidneys on the Hill Rally Dinner  
Meet with advocates from your state or region, practice for your meetings, and fuel up with a low-sodium dinner.



# Wednesday, July 12<sup>th</sup>

## Location:

Capitol Hill

## 8:30 a.m.

Group photo on the U.S. Capitol steps (northeast side)

## 9:00–11:30 a.m.

Meetings with your members in the Senate

## 12:15–1:15 p.m.

Congressional Briefing and hot lunch with no salt added and no nuts

## 1:30–4:00 p.m.

Meetings with your members in the House of Representatives



## What to wear?

**Dress business casual.**

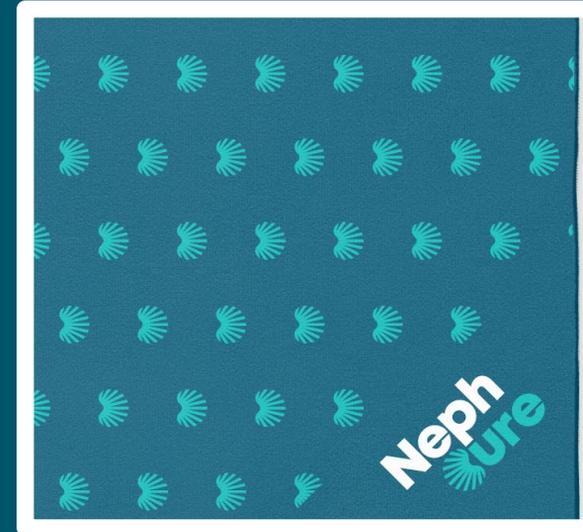
**Avoid jeans and t-shirts.**

**Wear comfortable shoes.**

**July in D.C. = hot and humid.**

**Indoors is air conditioned – bring layers.**

**Accessorize with NephCure ties and scarves!**



# Civics Refresh

**Matt Duquette**  
**Washington Representatives**  
**Health and Medicine Counsel, LLC**

# Quick Overview

## 3 Branches of Government

**Executive Branch (the Administration)**  
Enforces laws

**Judicial Branch (the Courts)**  
Interprets laws

**Legislative Branch (Congress)**

Creates and enacts laws

Congressional Authority: power of the purse; creating policy, oversight of federal agencies



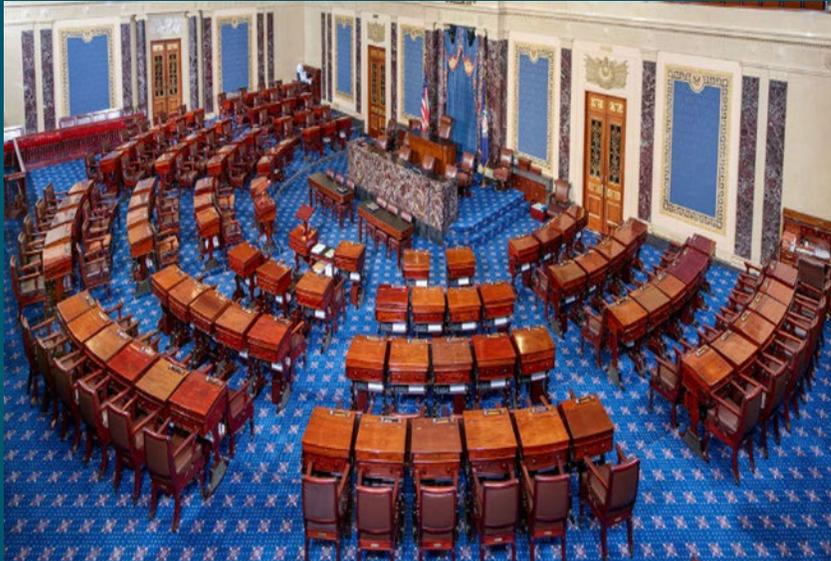
# Congress

## The United States Senate

Elected to 6-year terms

2 Senators from every state

100 Senators total



## The U.S. House of Representatives

Elected to 2-year terms

1 Representative from each district

435 Representatives total



# Congressional Authority

The power of the purse

Creating policy

Oversight of federal agencies

To become law, a bill must pass both the House and Senate and then be signed by the President

This process applies to bills in general as well "must pass" items like appropriations measures

Constituent voices during the legislative process is critical to helping them advance through their relevant committees

# Committees Relevant to RKD Policy Priorities

## United States Senate

Appropriations

Health, Education, Labor,  
Pensions

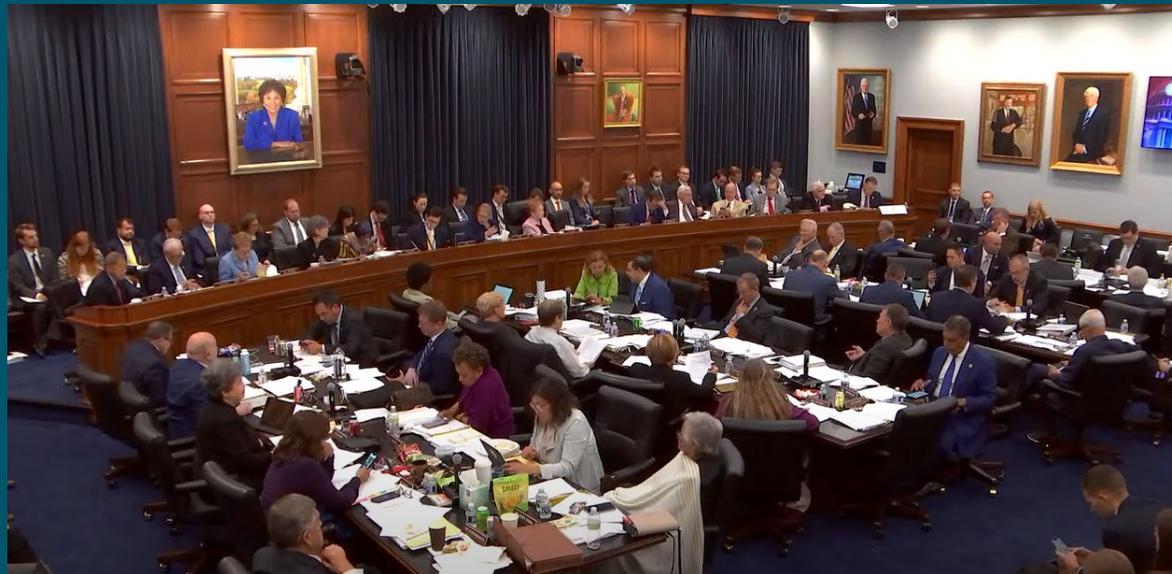
Finance

## U.S. House of Representatives

Appropriations

Energy and Commerce

Ways and Means

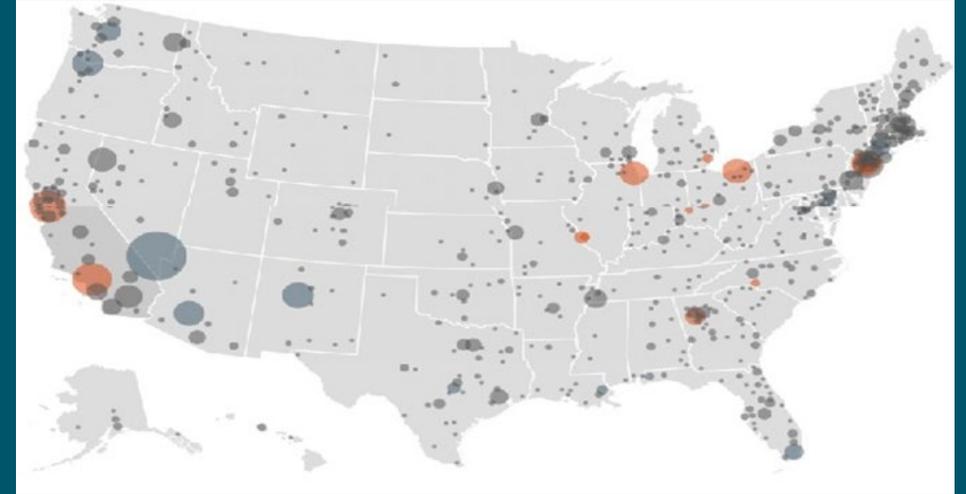


## Constituent voices

During the legislative process, hearing from constituent voices is critical for Members of Congress to help bills that improve rare kidney disease treatment and care to advance through their relevant committees

## Together

A coordinated nationwide effort by grassroots advocates can help advance research, increase research funding, and improve overall health and healthcare.



# Before your meetings

Starting today...

Learn about the New Era for Preventing End-Stage Kidney Disease Act.

Reference the issue brief and talking points.

Prepare your story and connect it to the New Era legislation.

## During Hill Day

Travel with your group to Congressional offices

In the meeting: The constituent must lead the discussion

- ➔ **Introduce the group**
- ➔ **Most importantly: tell your personal stories**
- ➔ **Introduce the New Era legislation and ask**
- ➔ **Use questions as a chance to follow up**
- ➔ **Get the staffer's business card**

Note: In previous years, we would have physical leave-behind materials to hand to the staffers, but offices now prefer to receive materials electronically beforehand or as follow up. HMC will be sending these materials to offices. Every advocate will have a copy of the leave-behind materials for reference and to use during the meetings, along with your prep packet.



# After your meetings

Debrief with your group and let the NephCure team know how each meeting went.

Discuss questions asked by staff. If you were unable to provide an answer, consult with the NephCure advocacy team. Use this as an opportunity to follow-up after any meeting.

Designate one person to send a thank you email to each lawmaker or staff for their time. Include answers to follow-up questions.

# **Washington Update and Review of Suggested Policy Asks**

**Philip Goglas II  
Washington Representatives  
Health and Medicine Counsel, LLC**

# Washington Update

1<sup>st</sup> Session of the 118th Congress

Start of a new Congress

Annual Budget and Appropriations Activity

Continued congressional focus on healthcare policy, including medical research and patient access

## Issue Briefs Provided to Your Members will Include:

Cosponsor the New Era of Preventing End Stage Kidney Disease Act

Support Appropriation Requests

Cosponsor Living Donor Protection Act, H.R. 2923/S. 1384

Cosponsor Safe Step Act, H.R. 2630/S. 652

Cosponsor HELP Copays Act, H.R. 830/S. 1375

# THE JOURNEY INTO A NEW ERA



Explosion of clinical trials with new clinical trial endpoints

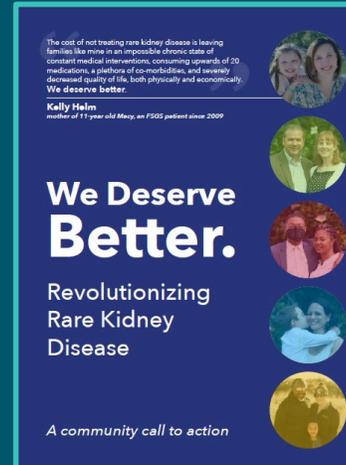


Presidential Executive Order: HHS Kidney Initiative

Dawn of a New Era in Rare Kidney Disease Treatment: Roundtable with Congress and HHS



We Deserve Better: Expert Policy Recommendations



NEW ERA IN PREVENTING END-STAGE KIDNEY DISEASE ACT

# THE NEW ERA OF PREVENTING ESKD ACT

## Background

H.R.7506 in the last Congress and was led by Rep. G.K. Butterfield (D-NC) and Rep. Gus Bilirakis (R-FL)

- 13 bipartisan cosponsors
- Rep. Butterfield retired

Rep. Gus Bilirakis (R-FL) and Rep. Terri Sewell (D-AL) have agreed to reintroduce *New Era* in the 118<sup>th</sup> Congress

Our Primary Ask of Congressional Offices (Ask #1):  
Cosponsor the New Era In Preventing End-stage Kidney Disease Act once introduced in the 118<sup>th</sup> Congress.



# THE NEW ERA OF PREVENTING ESKD ACT



Establish Rare Kidney Disease Centers of Excellence



Promote early intervention and improved diagnostic protocols



Address disparities in disproportionately affected communities



Promote provider education and access to specialty care



Expand rare kidney disease research



## Ask #2: Increase Funding for Medical Research and Education and Awareness Activities

Background: There are approximately 150 different types of rare kidney diseases, each affecting between 20,000 to 200,000 individuals nationwide. These are the most aggressive forms of kidney diseases that, if go undiagnosed or are not treated properly, often lead to kidney failure. Unfortunately, the causes of rare kidney disease are poorly understood, and many have no FDA approved treatments.

Solution: For more money to be spent on FSGS and NS, the size of the overall research funding needs to grow:

Provide \$50.924 billion for the National Institutes of Health (NIH). Provide a proportional increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute on Minority Health and Health Disparities (NIMHD) and support the expansion of the FSGS/NS research portfolio at NIDDK and NIMHD by funding more research into primary glomerular disease.

Provide \$11 billion for the Centers for Disease Control and Prevention (CDC) and \$6 million for the Chronic Disease Education and Awareness Program.

## **Ask #3: Continue to Include Focal Segmental Glomerulosclerosis (FSGS) in Defense Research Activities**

Background: Each year, the Department of Defense Peer Reviewed Medical Research Program designates a list of conditions that researchers can select from to apply for funding to study. NephCure volunteer advocates have so far successfully gotten FSGS on the list of designated diseases each year since 2016.

Inclusion on this list allows FSGS researchers to access up to approx. \$360 million in research funding each year. Researchers studying FSGS have successfully competed for over \$43 million for FSGS research to understand cause, diagnostics, and personalized medicines for FSGS. Even though it was included previously, doesn't guarantee it will be included every year.

Solution: Ask legislators to continue to support the inclusion of “Focal Segmental Glomerulosclerosis (FSGS)” and “Nephrotic Syndrome” as eligible for study through the PRMRP.

## Ask #4: Cosponsor The Living Donor Protection Act (LDPA) of 2023, H.R. 2923/S. 1384

Background: People who donate an organ to save another's life continue to face discrimination when seeking life, disability and long-term care insurance. Also, they may face discrimination in the workplace when requesting time off to recover from surgery.

Solution: Ask congress members to cosponsor the Living Donor Protection Act, introduced in the House by Representative Jerrold Nadler (D-NY-12) and in the Senate by Senator Kirsten Gillibrand (D-NY).

The bill prohibits the denial of coverage or increase in premiums of life or disability insurance for living organ donors. It would also ensure that living donors are protected by the Family Medical Leave Act (FMLA) which enables them to take time off work to donate a kidney and recover from the surgery without fear of losing their job.

Giving the gift of life is the most selfless decision anyone can make. When living donors are protected, more people will be encouraged to donate an organ.

## Ask #5: Cosponsor the Safe Step Act, H.R. 2630/S. 853

### Background:

Health insurers may force a patient to try a different, less expensive medication before they cover a medication they deem to be more costly. This process is called “step therapy” because the patient may have to go through one or more "steps" to access the medication their doctor prescribed or one the patient has used before with success.

In many cases, the step therapy medication may not work and the patient’s symptoms may get worse or take a longer time to heal.

### Solution:

1. This policy causes patients to experience irreparable harm by delaying treatment until failure on several drugs.
2. It is a cost-saving measure that ends up causing more expensive treatments to be needed.
3. This bill would allow requests for exceptions to be granted for required treatment that has been ineffective, treatment that is expected to be ineffective and delaying effective treatment would lead to irreversible consequences, treatment that will cause or is likely to cause an adverse reaction to the individual, and many more patient-centered exceptions.

## Ask #6: Cosponsor the HELP Copays Act, H.R. 830/S. 1375

Background: Through a loophole, many employer health plans deem certain covered drugs as “nonessential,” which means that the insurer will not count any cost-sharing toward the patient’s deductible and out-of-pocket maximum. This bill will require all private plans to count all cost-sharing for covered services to accrue to a patient’s deductible and out-of-pocket maximum.

Solution: This bill requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses toward the requirements. The HELP Copays Act is a two-part solution that:

1. Clarifies the ACA definition of cost sharing to ensure payments made “by or on behalf of” patients count towards their deductible and/or out-of-pocket maximum.
2. Closes the EHB loophole to ensure that any item or service covered by a health plan is considered part of their EHB package and thus cost sharing for these must be counted towards patients’ annual cost sharing limits.



# Making The Most of Your Capitol Hill Meetings

Mary Baliker  
Healthcare Consultant / Patient Advocate



# Policy Advocate

You can make a difference for kidney patients by:

Influencing public policy relating to kidney health.

Share your story. Make your voices heard!!!

Make change happen in government and across the nation.

# Meeting With Legislators

The democratic process involves citizens actively participating in the decision-making process in government.

Legislators want to hear from their **local constituents**.

Policy's get created in order to solve problems. Let's show our legislators how kidney disease policy and reforms will impact patients and their families.

**Share your story.** Remember, you are the expert in your own patient experience. Your story will have a strong and compelling impact. This is what they will take away from the meeting! The story makes the issue real.

# Tips



Arrive on time to your meeting and ensure you are prepared to utilize your time efficiently.



Do not be afraid to admit you don't know something the legislator asks.



Always be clear in your call to action. Ask at the beginning and again at the close of your conversation.



Know whether the bill has been introduced in the House or Senate. Track it at [Congress.gov](https://www.congress.gov).

# Plan & Practice Your Conversation

Be prepared

Prepare examples: connecting the story

Have a clear ask



Mary Baliker	Ryne Carney	Mark Pocan (D-WI-2)	Sydney Scott	1421 Longworth House Office Building
Mary Baliker	Ryne Carney	Tammy Baldwin (D-WI)	Brian Kaplun	709 Hart Senate Office Building



**Congressman Derrick Van Orden**  
**Wisconsin's 3rd Congressional District.**

# Meeting With Legislators Connecting Your Story to the Policy Asks!



**HELP Copays Act, HR.830/S. 1375**

**The New ERA of Preventing End Stage Kidney Disease Act**

**Living Donor Protection Act, H.R. 2923/S. 1384**

# Follow Up & Thank You

Follow Up with a thank you email, and or social media post that reiterates your ask.

Build relationships.





# Thank You!

Email Address: [mbaliker@gmail.com](mailto:mbaliker@gmail.com)

**Neph**  
**ure** for Rare  
Kidney  
Disease

# Making an Impact on Hill Day 2023

## Social Media Training



Nick Garlow, Rational 360

@NephCure  
#RKDWeek2023

# Why Use Social Media?



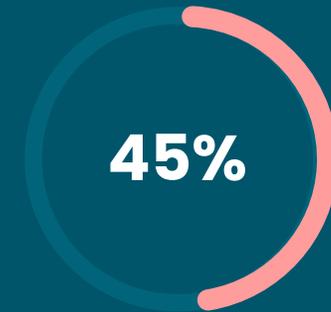
## UBIQUITOUS

**72%** of U.S. adults on the internet use social media websites.



## HIGHLY-ENGAGED USERS

**74%** of Facebook users check the site at least once daily and **51%** several times a day.



## PRIMARY NEWS SOURCE

**45%** of social media users learn more on political or social issues based on online content.

# The Advantages of Social Media



Live, Immediate & Fast



Open Source & Inherently Inclusive



Equal Voice for Everyone



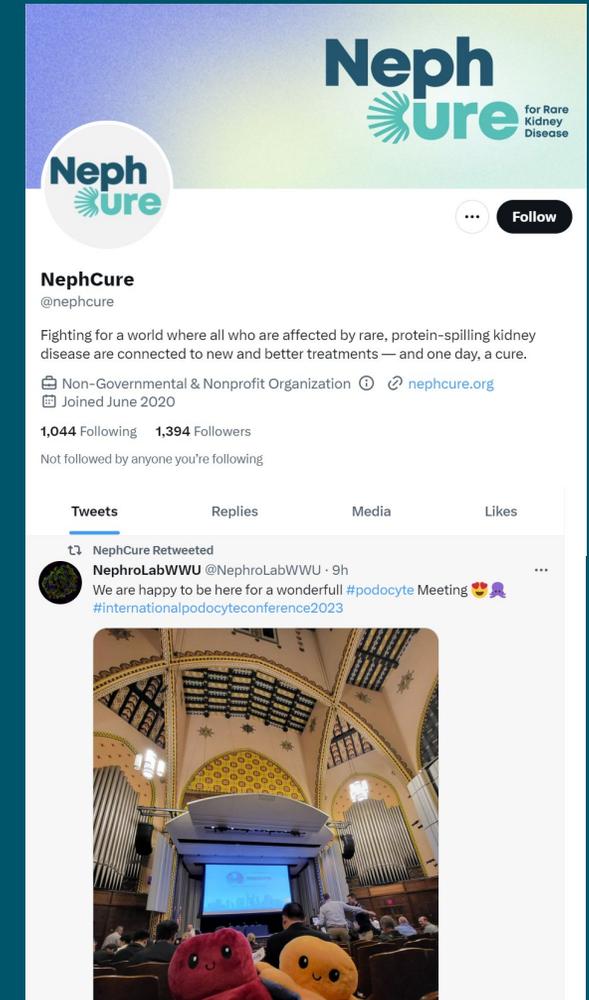
Wide Reach Beyond Your Personal Network



Distribute & Amplify Messages



Measurable & Engaging



# Engaging Policymakers on the Hill

Digital platforms offer a critical opportunity for individuals and advocacy groups to:

- (1) Highlight facts to educate policymakers
- (2) Tell policymakers why they should act

Be clear about what you're advocating for and communicate the result you want!

Tag policymakers with the “@” sign to alert them, thank them, or ask for action.





### Twitter

@NephCure

Main platform to **reach policymakers and journalists**. You can easily share concise bits of information, tag users, and include graphics and links to engage audiences.

**Skews younger** – Millennials and Gen Z.



### Facebook

@NephCure

Best platform for advocacy because Facebook provides features to **help build, organize, and easily mobilize large communities** around specific causes.

**Skews older** – Millennials, Gen X, and Boomers.



### Instagram

@NephCure

Great for **storytelling**. Video content shared via Reels or Stories have higher engagement over still photos. Tap into existing trends.

**Skews younger** – Millennials and Gen Z.



### TikTok

@NephCure

Effective medium for **personal stories and educational content**. Engaging short-form videos about personal rare kidney disease journeys can get others involved!

**Skews younger** – Millennials and Gen Z.

# Understanding Success



**LIKES:** How many people approve of your content.

**COMMENTS:** The conversation around your content.

**SHARES:** How many people shared your content with their followers.

Reactions

Likes, Comments, Shares

Impressions & Reach



**REACTIONS:** How your content is received by viewers. Available on Facebook and LinkedIn.



**IMPRESSIONS:** How many total content views did your content receive.

**REACH:** How many people saw your post.

**What's the difference?**  
People can see a post multiple times.

# Rules of the Road



## Profile

Choose a profile photo that visually represents who you are and a header photo showcasing what's new.



## Bio

Tell people what you do, what value you bring, and why they should follow you. Add a link to a website.



## Privacy Settings

Check your privacy settings to make sure that people who are not following you are able to view your content.



## Pinned Tweet

Pin a tweet to your profile! This is what you want your followers to focus on, it will be the first piece of content they see.



## Content

Always think before you write. When you can, personalize what you put out to differentiate your content.



## Visuals

Visuals matter. Social media posts with images, videos, and GIFs tend to perform better than those without.

# GET ENGAGED:

## 6 Key Steps to Writing a Good Tweet

1 Compress the Content

2 Use #RKDWeek2023 & #NewEra

3 @Tag People

4 Add a Link to Content

5 Include Images or Multimedia

6 Double Check Before You Hit Send!



Thank you @RepSusanWild for co-sponsoring the #NewEra Act! After a productive meeting with a rare kidney disease advocate today, Rep. Wild is now a proud supporter of HR 7506!



@NephCure

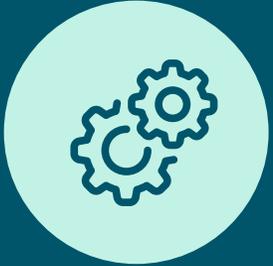
# GET ENGAGED:

## Next Steps: What to do on Hill Day

- ✓ **Post about the day** – Why are you there? What are you doing?
- ✓ **Take pictures** of the group, legislators, or offices and post about completed meetings.  
Note: Remember to ask to take the photo first as a common courtesy
- ✓ **Use the social media toolkit** to ‘click to Tweet’ during your visit.
- ✓ **Tag legislators and staffers**, thank them for meeting with you and encouraging them to act.
- ✓ **Use campaign hashtags** in every post – #RKDWeek2023, #NewEra, etc.
- ✓ **Retweet and like each others’ posts**, including the NephCure content!



# Final Reminders



**Think Before  
You Write**



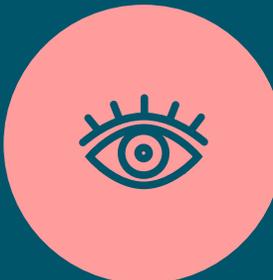
**Interact With Others;  
Don't Just Broadcast**



**Tag Legislators &  
Use #RKDWeek2023**



**Use Visual Content**



**Check Your  
Privacy Settings**

# Thank You!

Follow NephCure Social Media:

@NephCure & #RKDWeek2023



Turn on push notifications. Get alerts when NephCure posts!

# Your turn...

## Question & Answer

You may also send questions to  
[bdornan@nephcure.org](mailto:bdornan@nephcure.org).

**Thank you for all you do!**  
**See you soon!**

