



National
Association of
Neonatal
Nurses

NANN VIRTUAL LOBBY WEEK



MARCH
7 – 11, 2016

Taking Steps to Advocate and Act



Welcome to Virtual Lobby Week

Learn how to be an effective **NANN advocate** for babies, their families, and your profession.



Follow along on NANN's first Virtual Lobby Week
in support of **Senate Bill 2041**.



Why Advocate?

Why is NANN an active advocate?

It is part of our mission.

While every legislator is in favor of protecting the health of their constituents, they may not be familiar with the unique needs of neonates. NANN is *the* professional voice that shapes neonatal nursing. As neonatal nurses we

monitor progress on key issues,
work in coalition with other healthcare-related groups that share our goals,
and **raise our voice** in support of critical legislation.



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DAY 1 – The Issue

THE ISSUE:

Prematurity is the leading cause of newborn mortality and the second leading cause of infant mortality. Among those who survive, one in five faces health problems that persist for life.

A SOLUTION:

Senate Bill 2041, also known as S. 2041 and the Promoting Life-Saving Therapies for Neonates Act, will encourage the development of new therapies to ultimately improve the quality of treatment options available to premature newborns.



**NANN strongly supports Senate Bill 2041
Promoting Life-Saving Therapies for Neonates Act**



DID YOU KNOW?

- S. 2041 represents a proactive initiative to encourage and reward innovative research and development of therapies for neonates.
- The most recently approved drug for neonates was in 1999, nearly 17 years ago.
- S. 2041 was introduced by U.S. Senate by Senators Bob Casey (D-PA) and Bill Cassidy (R-LA).
- S. 2041 is currently co-sponsored by Senators Menendez (D-NJ), Booker (D-NJ), Capito (R-WV), and Donnelley (D-IN).

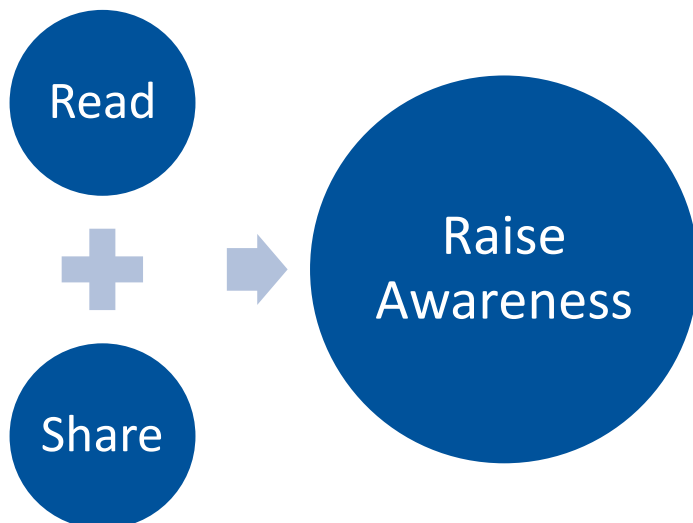


S. 2041 Would...

1. Close the treatment gap by stimulating the development of safe and effective drugs for a challenging and neglected pediatric population.
2. Ensure that new neonatal drugs address the most critical needs in the neonatal population by collaborating with multiple stakeholders, such as the NIH, the Critical Path Institute, and patient advocacy groups, to identify priority conditions.
3. Create a new incentive model by providing a transferrable “exclusivity voucher” to drug sponsors who successfully develop products for neonates. This voucher would enable the product sponsor to extend the exclusivity period on another drug by one year.

NANN members can educate themselves, peers, colleagues, coalition partners, friends, and family about S. 2041.

By reading and sharing any of the following materials, you can help bring awareness to the gap in innovation for neonates.



- ✓ [NANN Fact Sheet for S. 2041](#)
- ✓ [Newborn Health Initiative](#)
- ✓ [congress.gov](#)



DAY

2

TAKE ACTION

IN SUPPORT OF S. 2041

Taking Steps to Advocate and Act



DAY 2 – Take Action

HOW TO CONTACT YOUR SENATOR

- Not sure who your senators are?
 - Use the link below
 - <http://whoismyrepresentative.com>

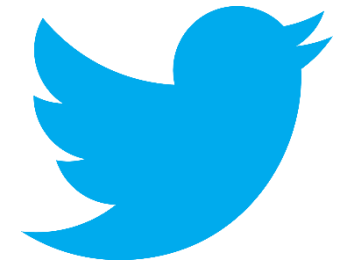
WAYS TO COMMUNICATE YOUR MESSAGE

- Reach out on social media
- Letter or email
- Phone Call
- Set up a meeting or attend a local town hall meeting or public forum



DAY 2 – Social Media Tips

- ✓ Tweet your representatives (e.g. [@SenGillibrand](#)) or tag them in a post with the action you want them to take or more information about the issue at hand.
- ✓ Share links to press releases, images from events, and NANN fact sheets.
- ✓ Use hashtags related to the issue you're trying to publicize (e.g. [#NANNAdvocacy](#) or [#s2041](#)).
- ✓ Social media is a conversation so share, comment, or reply to other people's posts.
- ✓ Follow NANN on [Twitter](#) and [Facebook](#) to stay up to date on the latest in neonatal nursing.





DAY 2 – Send an Email

EMAILING YOUR LEGISLATOR

1. Always have an “ask”
2. Keep correspondence concise and clear
3. Include a personal story or example
4. **To sign a letter to your senators on cosponsoring the vital legislation, S.2041 – The Promoting Life Saving New Therapies for Neonates Act, click [here](#).**



DAY

3

TAKE ACTION

IN SUPPORT OF S. 2041

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DAY 3 – MAKE A CALL



CALLING YOUR LEGISLATOR

You can call your policymakers or their staff to influence legislation. Legislators regularly ask their staff about constituent calls, and track how many constituents weigh in on either side of an issue.

- Contact information for your members of Congress, including their district office, is available on their [websites](#).

Remember, the more calls the better.

Ask others to make calls, too!



DAY 3 – Phone Script

SAMPLE PHONE SCRIPT FOR S. 2041

Hello, my name is XXXX and I am a constituent and a registered nurse in (your city/state)

I am calling to urge (Senator XXX) to support Senate Bill 2041, Promoting Life Saving New Therapies for Neonates Act of 2015. As a (registered nurse/NNP) who has dedicated (her/his) career to helping the smallest patients, I am convinced that we can do more to encourage the development of innovative neonatal treatments. The Promoting Life-Saving New Therapies for Neonates Act of 2015 marks a positive step towards a new era for innovation in neonatal health. Through the provision of an “exclusivity voucher”, Senate Bill 2041 will incentivize drug manufacturers to take on the vital research that would otherwise be too costly to perform.

Despite a growing need for new therapies, innovation in neonatal health has stalled due to the difficulty of clinical trials, the economic challenge of developing treatments for this category of patients and the complexities of the current regulatory system. This legislation proposed by your colleagues Senator Casey and Senator Cassidy would reverse this unacceptable status quo and provide the investment required to bring life-saving therapies for newborns into the 21st century.

As your constituent and as a neonatal nurse and a member of the National Association of Neonatal Nurses I urge you to support Senate Bill 2041, Promoting Life-Saving New Therapies for Neonates Act of 2015.

Thank-you for your attention to my request and I look forward to hearing (Senator’s XXX) position on this important piece of legislation.

(Leave your name, home address and phone number so the office can follow up with you)



DAY

4

TAKE ACTION

IN SUPPORT OF S. 2041

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SCHEDULE A MEETING

Scheduling a meeting is an effective way to influence policymakers and build relationships with senators, representatives, or their associated staff.





HOW TO SCHEDULE A MEETING

1. Email to request an appointment. If you want to meet in the district, send the request to the district office. Congressional member websites often have online submission requests available.
2. Call the office if you do not receive a response. Always identify yourself as a constituent. Provide your name and what you want to discuss. State when you would like to meet and who will accompany you.
3. Call or email to confirm the appointment.



DAY 4 – MEETING TIPS

1. Arrive on time
2. Bring two or three colleagues with you, if desired
3. Try to get your message across in 3-5 minutes
4. Be prepared to answer questions
5. Offer to be a resource for the Senator or the staff
6. Leave behind a business card and a one page document
7. Follow up with a thank-you note or email



DAY 4 – MEETING DO'S & DON'T'S

DO

- Use data and cases to support your cause- make it personal, tell a story
- Ask the stance of your representative on the issue and why
- Develop relationships with congressional staff
- Provide a one page document to leave behind
- Express your gratitude for their time spent meeting with you

DON'T

- Confront or pressure
- Be afraid to take a stand on the issue
- Overload the meeting with too many issues
- Be offended if your meeting is set up with a staff member



DAY

5

TAKE ACTION

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DAY 5 – NANN IN ACTION

- NANN Letter Urging HELP Committee Chairman Lamar Alexander to Support S. 2041
 - A letter on behalf of the National Association of Neonatal Nurses urges the Senate Health, Education, Labor, and Pensions (HELP) Committee Chairman Lamar Alexander (R-TN) to support S. 2041, the Promoting Life-Saving New Therapies for Neonates Act of 2015.
 - [Source.](#)
- NANN Letter Urging Senator Patty Murray to Support S. 2041
 - A letter on behalf of the National Association of Neonatal Nurses urges the Senate Health, Education, Labor, and Pensions (HELP) Committee Ranking Member Patty Murray (D-WA) to support S. 2041, the Promoting Life-Saving New Therapies for Neonates Act of 2015.
 - [Source.](#)



DAY 5 – NANN TESTIFIES

- On February 22nd, 2016 Allyson Kayton, MSN, APRN, NNP-BC represented NANN at a Congressional briefing in Washington, DC.

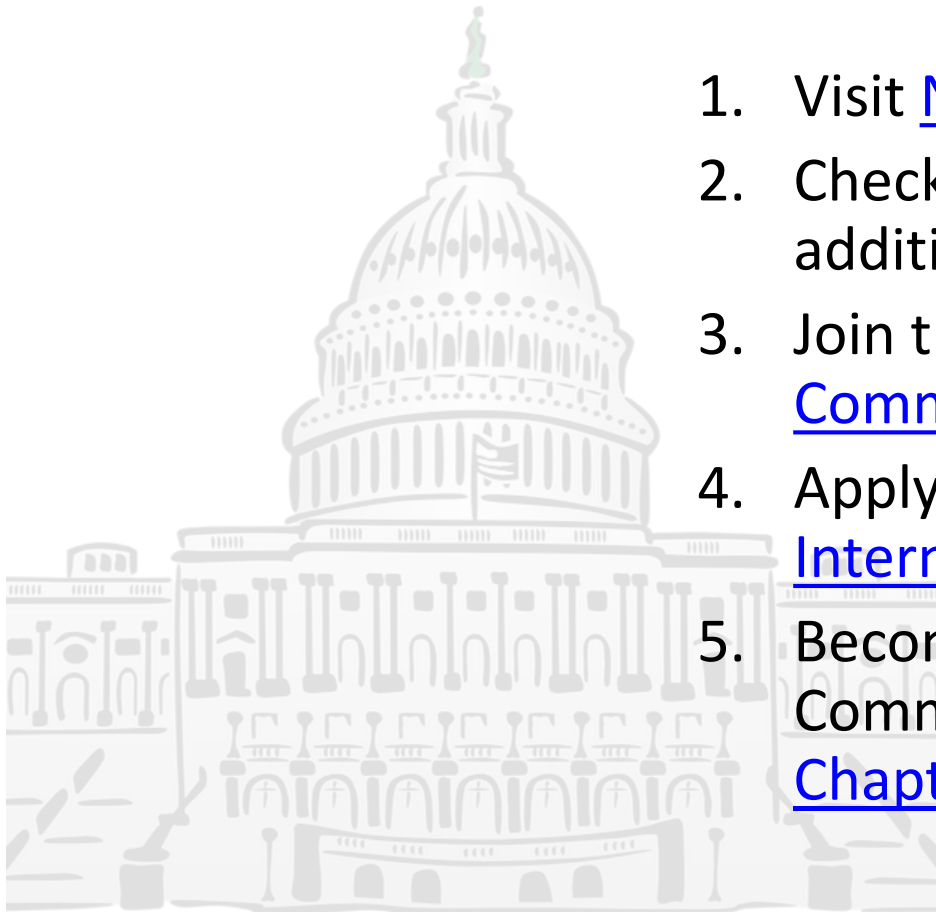


Ally was one of four speakers at this hearing in support of S. 2041.



INTERESTED IN LEARNING MORE?

1. Visit [NANN's Advocacy website](#)
2. Check out the [NANN Fact Sheets](#) for additional Issues
3. Join the [MyNANN Advocacy Community](#)
4. Apply for the [Nurse in Washington Internship](#) next year
5. Become involved in the Advocacy Committee of your [local NANN Chapter](#)





**THANK-YOU
FOR PARTICIPATING
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