

Bladder Rehab Buzz



Information and research news on Neurogenic Lower Urinary Tract Dysfunction

Welcome!

Welcome to the second issue of Bladder Rehab Buzz. This newsletter is brought to you by the Rehabilitation Research and Training Center (RRTC) at MedStar National Rehabilitation Hospital (NRH) in Washington, DC, in partnership with Children's National Hospital in Washington, DC, and The Institute for Rehabilitation and Research (TIRR) Memorial Hermann in Houston, Texas.

Make sure you visit our website [MedStarResearch.org/BladderRehab](https://www.MedStarResearch.org/BladderRehab) to find other materials on NLUTD, such as factsheets, tools to help in monitoring and decision-making around urinary symptoms, podcasts and scientific articles authored by our research team. In this issue, we will update you on our ongoing research studies, introduce you to our Consumer Experts, and review our newly developed urinary symptom questionnaires.



Meet our Consumer Experts

Elizabeth Davis

Elizabeth (Liz) Davis has been an advocate within the disability community for over a decade. She is the proud mom of three children, one of whom (Spencer) has spina bifida. Spencer competes in adaptive sports including wheelchair basketball, sled hockey, tennis, swimming, and wheelchair track, and is an avid baseball fan. Liz has worked with the team at Medstar Health Research Institute since 2014 as a Consumer Expert assisting us in our research related to neurogenic bladder. Liz previously worked in the Health Division of the Office of Management and Budget (OMB). She holds a Masters degree in Public Policy from the University of Chicago's Irving B. Harris School of Public Policy and has Certificate in Health Administration Studies from The University of Chicago's Graduate Program in Health Administration and Policy. She lives in McLean, VA with her husband and children.



Harsh Thakkar

Harsh Thakkar is a coordinator for the SCI Peer Mentoring Program and the Adaptive Fitness Program at MedStar NRH. Also, he is the president of the United Spinal Association Metro DC Chapter. Harsh is an avid advocate for the disability community since his own injury back in 2005. Harsh has worked with the Disability Office of Washington DC to assist with disability sensitivity training and has also spoken at congressional hearings on various topics such as complex rehabilitation technology and insurance caps. Harsh believes through systematic changes and a collective power that more individuals with disabilities will have improved ease of access for a better quality of life.



Mark Neagli

Mark Neagli previously worked for 18 years in the non-profit sector for the National Multiple Sclerosis Society. He provided leadership for the organization with responsibilities that included overseeing fundraising, programming, advocacy, and volunteer engagement. He is a father of 5 and grandfather to 8 grandchildren. His hobbies are cycling and spending time with friends and family. Since 2016, he has lived with a C3 level incomplete spinal cord injury due to a fall.



News you can use

Bladder Buzz Podcast

Our first podcasts “What’s neurogenic bladder? For patients and families” and “What’s neurogenic bladder? For healthcare professionals” are now available.

Find us on Apple Podcasts, Google Podcasts, Spotify or Amazon music. You can also listen online <https://bladderbuzzpodcast.buzzsprout.com/>

Stay tuned for monthly podcasts on a variety of topics

Urinary Symptoms Questionnaire

Sometimes it’s hard to know how to manage your urinary symptoms and when to seek medical attention. The bladder health research team at MedStar NRH have developed three urinary symptom monitoring tools to allow people to monitor their symptoms and facilitate decision-making around urinary symptoms. The three tools are specific to bladder management method (for those who: 1. primarily void; 2. use an intermittent catheter; or 3. use an indwelling catheter) and can be used at home and also shared with your healthcare provider. See the link below: <https://www.medstarhealth.org/mhri/medstar-research-networks/medstar-neuroscience-and-rehab-research-network/bladder-rehabilitation-research-training-center/resources/>

In Partnership with

 **NBRG**  **MS**  **United Spinal Association**  **SPINA BIFIDA ASSOCIATION**

nbrg.org | nationalmssociety.org
unitedspinal.org | spinabifidaassociation.org

What is Neurogenic Lower Urinary Tract Dysfunction (NLUTD)?

NLUTD is defined as a loss of sensation and voluntary control of the bladder, commonly resulting from any of a variety of neurological conditions, including spinal cord injury and disease (SCI/D), spina bifida (SB), Parkinson's disease, stroke, multiple sclerosis (MS), traumatic brain injury and others.

Research Project 1

Study Title: Intravesical Probiotic (Lactobacillus) for Urinary Symptoms Among People with Neurogenic Lower Urinary Tract Dysfunction Who Use Indwelling Catheters

The objectives of this study are to:

1. Describe the bacteria normally present in healthy urine; and
2. Estimate the effect of intravesical *Lactobacillus GG* probiotic dose on urinary symptoms

Participants must be:

- Diagnosed with neurogenic bladder (SCI, MS, SB, Stroke etc.);
- Use indwelling catheterization for bladder management
- 18 years or older;
- Have a history of 2 or more episodes of urinary symptoms in the past year.

If you are interested or have questions, please contact:

Margot Giannetti
Margot.Giannetti@medstar.net
202-877-1071

Research Project 2

Study Title: A Randomized Controlled Trial of Transcutaneous Tibial Nerve Stimulation (TTNS) for NLUTD.

The objective of this study is to prevent deterioration in bladder function after acute spinal cord injury by providing a feasible, non-pharmacologic intervention to be performed at home.

Participants must be:

- Diagnosed with a Spinal Cord Injury or disease;
- Level of injury T1-T9;
- Aged 18-65;
- Admitted to inpatient rehabilitation within 4 weeks of SCI/D at MedStar National Rehabilitation Hospital (Washington DC), or TIRR Memorial Hermann (Houston, TX).

If you are interested or have questions, please contact:

MedStar National Rehabilitation Hospital:
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202-877-1591

TIRR Memorial Hermann:
Vanessa Bernal
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Research Project 3

Study Title: A Mixed Methods Assessment of the Impact of the Connected Catheter™ on Quality of Life and Participation

The objectives of this study are to:

1. Evaluate if the burden of Neurogenic Lower Urinary Tract Dysfunction (NLUTD) on quality of life, participation is affected by type of bladder management; and
2. To explore the user experience of the Connected Catheter in terms of quality of life.

To be included in this study, participants must:

- Have previous participation in a Connected Catheter study;
- Be male;
- Be 18 years and older;
- Have a diagnosis of neurogenic lower urinary tract dysfunction; and
- Be a caregiver of a participant that previously participated in a connected catheter study

If you are interested or have questions, please contact:

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Contact Us

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Visit

[MedStarResearch.org/BladderRehab](https://www.MedStarResearch.org/BladderRehab)



The BluRB

The Society Section

Pumpkin carving for Halloween is a fun tradition for many people. Our very own Dr. Argy Stampas decided to carve out spooky, angry bladder with a UTI in his pumpkin this year, while Dr. Suzanne Groah made a barfing pumpkin.



For more information about our research studies [CLICK HERE](#)

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