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Are you in need of masks?

SBRN has free packs of 5 white cloth masks to distribute.

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From The Desk Of

Roberta Kestenbaum



October is Spina Bifida Awareness Month! SBRN has some new events and activities to participate in this month, including **our first ever virtual comedy show: *Hilarious Healthcare Hacks***. Laugh along with 5 funny comedians on Sunday, October 18. [Learn more>>>](#)

We'll also be holding some fundraising events and contests. Win prizes and support SBRN's services and programs! First up, we are partnering with Express Feedback for Good on a **fun project that won't cost you a cent** – all you have to do is give quick feedback on products and services that you already use! SBRN receives funds for every opinion you give. [Learn more>>>](#)

And then in November, we all get to vote! Make sure to register and be sure to exercise your right to vote. Learn about your voting options below. Also in this issue, read about Urinary Tract Infections, as well as thoughts on how COVID-19 will affect working from home moving forward.

Support SBRN by Sharing Your Opinions

We are partnering with Express Feedback for Good on a fun, easy initiative to support our programs. Each time you provide feedback, SBRN receives \$\$!

It's fast, free, secure and impactful! **Check it out!**

Text "SpinaBifida" (without quotations) to 31996 to learn more, or go to:

<https://hundredxinc.com/efg-spinabifida>



Urinary Tract Infections (UTIs)

Why People with Spina Bifida are More Susceptible to UTIs

Urinary Tract Infections (UTIs) are the most common bacterial infections in the U.S. And as anyone with spina bifida knows, they are even more common for people with spina bifida. There are two types of UTIs: bladder infection (cystitis) or kidney infection (pyelonephritis). Infections occur when bacteria gets into the urinary tract, which includes the bladder and the kidneys. The urinary tract is where urine is produced, collected and eliminated from the body.

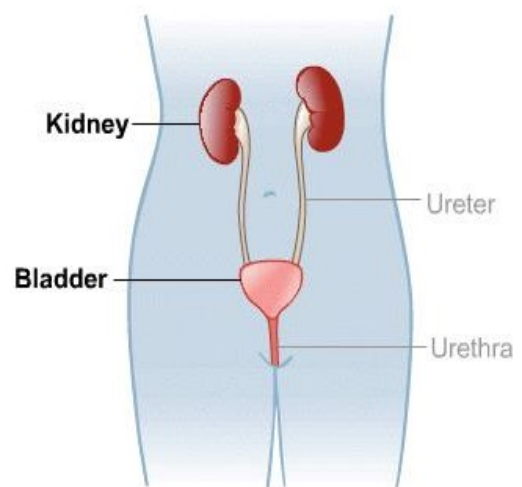
Children and adults with spina bifida may be more prone to UTIs due to the lack of feeling and control of their bowel and bladder. They may not be aware when their bladder is full and they may not be able to empty it fully. The leftover urine can become stagnant and smelly and can become infected. The lack of sensation may prevent them from feeling the symptoms of a UTI which could lead to a delay in diagnosis and treatment. Over time, stones may develop and infections could cause kidney damage.

Although there are a number of symptoms that are typical of UTIs, sometimes symptoms are not present (asymptomatic) and sometimes similar symptoms do not indicate a UTI. Therefore, it is important to recognize symptoms and have them checked by a doctor for confirmation of a UTI.

Symptoms

Common symptoms include:

- Fever – for infants, this may be the easiest way to tell
- Fussiness or excessive sleepiness (for infants)
- Generally not feeling well or failure to thrive (for infants)
- Pink or red, cloudy or smelly urine
- Pain with catheterization or burning sensation with urination
- Incontinence or an urge to urinate more
- Decreased appetite, nausea and vomiting
- Pain in back or lower stomach



Urinary Tract Infections (UTIs) *(continued)*

Identification and Treatment

UTIs are not identifiable by symptoms alone. If a UTI is suspected, medical practitioners will perform a urinalysis and a urine culture on a urine sample. Urine samples can be collected through catheterization or a “clean catch” urine sample. If the lab results indicate that there is a UTI, the infection will most commonly be treated by antibiotics. It is very important to complete the full dose of the antibiotic even if the symptoms go away to make sure that the infection is gone.

Hard to Treat or Multiple Infections

Sometimes children and adults experience multiple infections over time. In this case, prophylactic (preventative) daily low dose antibiotics may be prescribed for months, sometimes years. This can be effective for preventing future infections but not for treating current infections. This is often used for children who have reflux or for anyone with kidney damage.



Others may experience stubborn infections that are hard to get rid of. This may be due to antibiotic resistance, when the infections no longer respond to the oral antibiotics. Doctors may need to try different types of antibiotics to find one that will be effective. Antibiotic resistance in general is making it more difficult to treat infections.

Prevention

Because of the risk of multiple UTIs and/or kidney damage, urological care needs to begin at an early age, even infancy. Starting catheterization early can help preserve kidney and bladder function. In addition, it is important to be vigilant about:

- *Removing all urine from the bladder* – When the bladder is not adequately emptied and the urine sits for a long time, the risk of infection increases. Clean intermittent catheterization (CIC), several times a day, can reduce this problem. Make sure that the appropriate catheter size and type are used.
- *Avoiding constipation* – Excessive stool in the rectum can increase bacteria which can cause infection. Bowel management programs to ensure regular soft stool are recommended.
- *Being careful about hygiene* – This is important for CIC as well as for bowel movements.
- *Drinking water* - Research suggests that drinking more water can help prevent UTIs.

Urinary Tract Infections (UTIs) *(continued)*

REMEMBER:

See your doctor if you have any symptoms that might indicate a UTI or if you suspect your child might. Testing for UTIs is a fairly simple process and treatment can begin quickly.



This information is presented for the purpose of education and is not meant as a substitute for medical advice or care from a physician or other healthcare providers. Contact your healthcare provider with questions about care.

References:

- * *Pediatric Urinary Tract Infections and Catheterization in Children with Neurogenic Bladder and Bowel*, Spina Bifida Association.
- * *Spina Bifida & Urinary Tract Infections (UTIs)*, Spina Bifida Hydrocephalus Ireland.
- * *Spina Bifida and Urological Management*, Intermountain Primary Children's Hospital.
- * *Urinary Tract Infections (UTIs)*, Spina Bifida Association New Zealand.
- * *Urologic Care and Management*, Spina Bifida Association.
- * *UTIs are Getting Tougher to Treat*, R. Rubin (2015), from the WebMD Archives.
- * *What Parents Should Know: Urinary Tract Infections in Young Children with Spina Bifida*, National Center on Birth Defects and Developmental Disabilities, CDC.

It's Your Right to Vote: How to Do It Safely in New Jersey

Have you voted yet? It's time to exercise your right to vote! The 2020 General Election is scheduled for **Tuesday, November 3**. We will be voting for President, members of Congress as well as State and local representatives. There is a lot at stake in this election: everyone needs to be represented!

For health and safety reasons, if you are worried about waiting in line to cast your vote, there are other options. In New Jersey, there are a variety of ways to vote early. Choose the option that works best for you and make sure to get your ballot in. (For info about voting in other states, go to: [How to Vote Safely in all 50 States](#).)

Voting in New Jersey

Are you registered?

The last day to register to vote in NJ in the November General Election is October 13. Go to the **2020 NJ Voter Information Portal** (<https://vote.nj.gov>) to do it online! Not sure if you are registered or if it's up-to-date? You can check that on the portal too.



How to get a ballot

All active registered voters in New Jersey will automatically receive their ballots in the mail, at the address where the voter is registered. If you haven't received a ballot by October 12, track your mail-in ballot status online at <https://vote.nj.gov> or contact your County Clerk, listed on the [County Election Officials](#) page.

What are my options for how to vote?

There are 4 different ways to return your ballot:

1. **Mail:** It must be postmarked on or before November 3 and be received by your county's Board of Elections on or before November 10.
2. **Secure Ballot Drop Box:** Place your ballot in one of your county's secure ballot drop boxes by 8:00 p.m. on November 3.
3. **Board of Elections Office:** Deliver your ballot in person to your county's Board of Elections Office by 8:00 p.m. on November 3.
4. **Polling Place:** Bring your ballot to your polling place by 8:00 p.m. on Election Day, November 3. Remember only you, the voter, can bring your ballot to your polling place on Election Day.

You can find the locations of drop boxes, polling places and the county Board of Elections office on the portal at <https://vote.nj.gov>.

It's Your Right to Vote: How to Do It Safely in New Jersey *(continued)*

What do I do with my ballot? Follow the instructions carefully!

There are two envelopes – it is very important that you use both of them. After you make your choices on the ballot, you must place your ballot in the smaller envelope and seal it. Then fill in your information and sign it. Then you must place it in the larger envelope. You can then mail it – you do not need a stamp, postage is already paid. Or you can choose to drop it off at the County Board of Elections office or bring it to the polling place on Election Day. Someone else may bring your sealed ballot to the Board of Elections, but they must sign the outer envelope. Only you can bring the ballot to the polling place on the day of the election.

Can I Vote In Person?

You may choose to vote in person at your polling place, from 6:00 a.m. to 8:00 p.m. on Election Day, November 3, and you will be provided a provisional paper ballot. Accommodations will be made for people with disabilities to use an accessible voting device. Or, you can return your vote-by-mail ballot at your polling place.

Where Can I Get Additional Information or Help?

Visit <https://vote.nj.gov> for full details, drop box and polling locations, and more answers to frequently asked questions. You may also contact your local election officials, or call the Voter Information and Assistance Line at 1-877-NJ-VOTER (1-877-658-6837).

Remember, you can turn in your ballot as soon as you receive it. Just fill it out, seal it, sign it and use the two envelopes provided. There's no need to wait and doing it as early as possible will ensure that it will be received in time!



How will COVID-19 Affect Work-from-Home Policies?

When the pandemic is finally over, will things go back the way they were or will we use what we've learned to create more equitable, accessible workplace options? For some people with mobility impairments, who may have transportation issues or other health problems, the opportunity to work from home (wfh) can mean the difference between working and not working.

Andrew Pulrang suggests in a Forbes article ([“3 Ways The COVID-19 Pandemic Could Change Disability Policies And Practices”](#)) that the pandemic may lead to a wider acceptance of working from home. Pulrang points out that on the one hand, it's nice that wfh is becoming more acceptable, but on the other hand, it's frustrating that this acceptance has only come about because of the pandemic when people with disabilities have been fighting for this option for decades. He also points out that wfh is not a replacement for community accessibility.

“Online and work from home options have sometimes been sold to disabled people as an alternative to making workplaces more accessible and less discriminatory. This is not what we are looking for. Working from home should never be treated as a substitute for community accessibility, accessible transportation, and community integration. But for some disabled people, working from home is a great option ... just as is for many non-disabled people for other reasons.”



Although working from home could always have been considered a “reasonable accommodation” in accordance with the Americans with Disabilities Act (ADA), employers have often been reluctant to consider it. Now that it has become more commonplace and employers have learned how to accommodate remote workers, it may bust open some stereotypes and employers may be more willing to consider it as a viable option moving forward for those who want it. Additionally, if employers are more accepting of remote work arrangements, they may create more wfh options which could open up more employment opportunities since people would not be limited to working locally and could accept jobs anywhere.

It remains to be seen whether opportunities will change for people with disabilities after the pandemic is over. Will employers be more inclined to offer more remote work options? Perhaps employers who had a good experience with employees working from home and who invested in the technology needed will be more inclined to continue to offer remote options. We should look to these employers for insight on how to do wfh effectively while continuing to advocate and educate those who are resistant. It is also important to continue to advocate for reasonable accommodations in the office. Wfh options do not excuse employers from creating an accessible workplace when that is the better option.