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From The Desk Of Roberta Kestenbaum

All of us at SBRN hope that you and your family are staying safe and healthy. These are strange times, like nothing we have ever experienced before. Although we are in the midst of a public health crisis with the coronavirus pandemic, there are things we can do together to help our friends, neighbors, and community.

Our community's health and wellness is important to us. So SBRN has taken steps to ensure the health and safety of our staff, volunteers and clients. We have closed the office, but we are still available for support and information. You can email us at info@thesbrn.org or Contact Staff members directly.

To help people navigate through the overwhelming amount of information that is out there, we have set up a special Resources page on our website with dependable resources regarding COVID-19, including information for people with disabilities as well as mental health resources. Staying informed from reliable sources can help everyone make the best choices and alleviate some anxiety.

We also provide additional information here in this newsletter, including articles about coronavirus and spina bifida, scams to watch out for and fun things to do online while staying at home. Be sure to follow us on Facebook for continual updates on relevant information as well as more lighthearted fare.

In addition, we will continue **advocacy efforts** to protect the rights of people with disabilities. We have been contacting representatives at the state and federal levels, as well as supporting other advocacy groups, to advocate for issues such as ensuring that social security recipients receive stimulus checks, that the rights of students are protected against the weakening of the IDEA and the rights of all people with disabilities are protected regarding medical treatment and rationing.

We understand that social distancing can sometimes be a lonely process. To help with that, we are starting a new virtual Chat Group, called "Support, Boredom Relief and Networking" on alternating Tuesday afternoons and Thursday evenings. More information about how to join will be available soon.

We can all help each other to feel safe and supported during these troubling times. Make a phone call, send a text, arrange to Facetime, and reach out to someone you haven't spoken to in a while or who might be alone. **Practice physical distancing but stay socially connected!**





CORONAVIRUS AND SPINA BIFIDA

What is the coronavirus?

The novel coronavirus (COVID-19) is a respiratory illness that spreads from person to person. The main symptoms are coughing, fever and difficulty breathing.

Is a person with spina bifida, hydrocephalus and/or a shunt at higher risk of getting coronavirus?

We have been informed by a number of physicians and public health experts that having spina bifida, hydrocephalus and/or a shunt does NOT increase your chances of getting coronavirus, unless there are other risk factors involved (see the next question).

What conditions/factors increase the risk of contracting coronavirus?

The following increase the risk for all populations: over 60 years old, heart disease and/or hypertension, diabetes, breathing/respiratory issues such as asthma, suppressed immune system, and kidney or liver disease. Extreme scoliosis may also put a person at greater risk if the curvature of the spine affects the lungs.

Is there anything special that a person with spina bifida should do to prevent getting coronavirus?

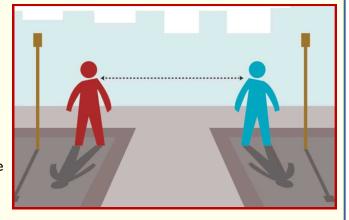
Everyone should practice good hygiene by thoroughly washing hands, coughing into their elbows, and not touching their faces. Experts suggest that since the coronavirus is spread by secretions, it is particularly important for people with spina bifida to practice extra careful hygiene for bowel and bladder routines, including washing hands before and after.

Is it safe to see the doctor if a person is experiencing symptoms that are not related to the coronavirus?

It is still very important to seek medical attention if someone thinks they have an infection, are experiencing pain, are having problems with their shunt or any other symptom related to spina bifida or hydrocephalus. If it is an emergency, call 9-1-1. Otherwise, call the doctor's office and they can advise on the safest way to be taken care of.

What is SOCIAL DISTANCING?

- * "Social distancing" is a public health measure used to keep people from interacting too closely or frequently in order to stop or slow down the spread of a highly contagious disease.
- * It means that people should avoid crowds, maintain at least 6 feet from others and stay home as much as possible.
- * It is important to practice social distancing with everyone (not just people with symptoms) because people can spread the virus before they begin to show symptoms.

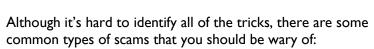






CORONAVIRUS SCAMS

Be aware! Coronavirus scams are alive and flourishing. From selling "cures" or "diagnostic tests" to offers to help you get your rebate, scammers are working hard to get your money and/or personal information. There have even been reports of people knocking on doors and offering tests for money. The Federal Trade Commission (FTC) reported that complaints related to coronavirus have soared in the past few weeks.





- Calls asking you to verify information in order to **receive a stimulus check** from the government. Hang up and do NOT give any information. No one from the government will contact you about your stimulus payment or ask for personal information.
- Claims that they can get you **money from the government sooner** if you give money or personal info. They can't.
- Offers to reserve your place in line for testing if you send money. Don't do it!
- Offers of **in-home vaccines**, **tests or treatments**: there are currently none of these that are available.
- Offers of something like "health kits" that will prevent, detect or cure the virus, which ask for credit card or other personal information. Sometimes they will appear to come from reputable or known companies. Again, there are none available through the mail.
- Any type of offer which sounds too good to be true and which **asks for money up front**, especially if they ask for prepaid credit cards or gift cards.
- Offers to clean and sanitize your house and then they ask for money up front or personal info.
- Calls or emails asking for donations. Although many legitimate agencies, groups and individuals are seeking support, there are many scams as well. If it's an agency, check with something like <u>GuideStar</u> or the <u>BBB</u> to see if they are legitimate. If it's an individual (for example, someone on GoFundMe), be wary about giving money unless you know the person or situation.
- Emails that try to get you to **click on a link**. Don't click on any links or download any files from unexpected or unknown emails because it could lead to exposure to malware.
- Phone calls or emails by someone impersonating a government agency (such as Social Security).
 Do not give personal information like bank accounts and social security numbers. Government agencies will not call and ask you for that information.

CORONAVIRUS SCAMS (continued)

One final note: Beware of **fake websites** – if you google "coronavirus cures" you will probably come across some websites offering products that will cure (or prevent) the virus, and they will be happy to take your credit card info. They may also infect you with malware. Although some companies may actually send you some sort of product (including herbal remedies, aromatherapies, home-made hand sanitizers), they are not cures. There are no known cures.

CORONAVIRUS SCAMS!

In general, follow these three guidelines:

- > Be wary of anyone offering items that will prevent, diagnose or treat COVID-19!
- > Do not give bank account info, credit card numbers or social security numbers to anyone over the phone unless you are sure you know who it is!
- > Do not wire money, send gift cards or prepaid credit cards to anyone that you don't know!

More information from the Federal Trade Commission: Coronavirus Scams: What the FTC is Doing

CORONAVIRUS TIPS

Tip # I - Some stores, like Stop & Shop and Target, offer specific hours for seniors to shop. If you call the store, they may offer it for people with disabilities as well.



Tip #2 – If you are admitted to the hospital or are being tested for COVID-19, be sure to find out if the gloves and masks are latex free.





Why the Disability Community Matters When Counting the 2020 Census

What is the Census?

Every 10 years, the federal government must carry out a constitutionally mandated count of every person living in the United States. The Census is happening now and it's vitally important for everyone to participate. The deadline for participation is August 14, but why not complete it now, while we are mostly staying at home!

Why does it matter for people with disabilities?

The Census Bureau has identified people with disabilities (pwd) as being a "hard-to-count" population, which

means pwd might be underrepresented in the count. This matters because the census information determines how more than \$800 billion a year in federal funding are spent and distributed. This includes many key programs that support and protect pwd including: Medicaid, Statewide Independent Living Councils, Education Grants to States for Students with Disabilities, Supplemental Nutrition Assistance Programs,

Vocational Rehabilitation State Grants Programs and others.

<u>Watch this video</u> from Disability Rights New Jersey about how it is important for people with disabilities to be counted.

How do people participate?

The Census Bureau has already begun sending information to every household. Households can complete the form online using a desktop computer, a laptop, a tablet or a smart phone. People can also respond by phone or by mail. Instructions are on the materials that have been sent to the homes.

Fill out the census online here: https://2020census.gov/

What questions are asked in the Census?

The basic census is very simple. It asks about age, Hispanic origin, race, sex, number of individuals living in the household and if the household owns or rents. It does NOT ask about disability or citizenship. Questions on disability are primarily asked in the American Community Survey (ACS), which is sent to a subset of households every year. This information is used by local, state and federal governments to determine how and where money is spent.

How will my information be used?

Sometimes people are reluctant to participate in the census because they believe that the information they provide will be used against them in some way. It is important to know that your answers are kept anonymous and cannot be shared or used to identify individuals. By law, your information cannot be used against you by any agency or court. Information is used only to produce statistics.

How can I avoid scams?

It's important to watch out for scams where people try to get your information by pretending to be a census worker or another agency that wants to help with the census. You may get emails that ask you to click on a website that looks real but is actually fake. They may try to get your personal information or infect your computer with malware. If you are not sure, do not click on it. To protect yourself, remember that the Census Bureau will never ask for social security numbers, bank account info or money, so never give that information through email or phone.

Additional Information about the Census can be found here:

U.S. Census 2020: https://2020census.gov

NJ Census 2020: https://www.nj.gov/state/census.shtml

Arc of NJ's Census Info for People with Disabilities: https://www.thearcfamilyinstitute.org/spceial-campiangs/census-2020.html





Fun Things to Do and See from Home

Feeling bored or frustrated that you can't get out? Explore the world from the comfort of your couch. Here are some online virtual tours and activities from around the world to engage in. Visit the Louvre in Paris, enjoy beautiful botanical gardens, watch some animals at the zoo or explore space. There's something for everyone!

Art & Museums

- <u>Smithsonian Institutions</u> Virtually explore the Smithsonian Museums' collections and exhibits, including a virtual tour of the <u>Museum of Natural History</u> and the <u>Science Education Center</u> for fun games to play online.
- ◆ The Louvre Enjoy a virtual tour of exhibits at the Louvre in Paris.
- National Gallery of Art Virtually explore the exhibits, find lessons and online courses for adults and kids.
- Links to virtual tours of famous museums from around the world
- ◆ The Intrepid Sea, Air & Space Museum Join the Intrepid Museum's curators as they take you to areas of Intrepid that are often off-limits to the public.
- ♦ Check out some <u>free online books</u> from the Guggenheim Museum in NY.
- Winchester Mystery House Explore this architectural wonder and historic landmark in San Jose, CA.





Health, Physical Activity and Disability

- National Center on Health, Physical Activity, and Disability Find articles, videos, and more to keep you healthy, active, and engaged.
- ♦ Listen to <u>disability-focused podcasts</u>.
- Watch the Spina Bifida Association's <u>SB-You: Get Fit and Stay</u> <u>Healthy</u> webinar.
- Get moving with the <u>Best Chair Exercise Videos</u>.



Fun Things to Do and See from Home (continued)

Space Centers and Tours

- ♦ Kennedy Space Center Engage in a virtual reality experience that takes you to restricted access areas that brings space artifacts to life.
- <u>Smithsonian National Air and Space Museum</u> Take a virtual tour and enjoy activities and games you can play.



Zoo's Planetariums and Aquariums

- <u>Cape May County Zoo</u> Watch their virtual Zoo School where they feature a short clip of a different animal and teach you all about it.
- San Diego Zoo Watch webcams of giraffes, tigers, apes, pandas and many more.
- Planetariums Check out what planetariums from all over have to offer.
- Monterey Bay Aquarium Watch webcams of their aquatic exhibits.
- Georgia Aquarium Watch webcams of whales, penguins, gators and more.



Cooking at Home

• <u>Virtual cooking classes</u> – You can try out new recipes or just enjoy watching others cook.



Gardens from Around the World

- Virtual Garden Tours Eight absolutely stunning garden tours from around the world.
- <u>U.S. Botanical Gardens</u> The plant displays and exhibits are different each time you come.
- ◆ <u>Longwood Gardens</u> Enjoy videos of what's in bloom, and engage in online classes and activities for all ages.





