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SAVE THE DATE



for Adults with Disabilities

September 17 - 19

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From The Desk Of *Roberta Kestenbaum* 

We are happy to announce that we will be hosting the **annual Empowerment Retreat** for adults with disabilities on September 17-19. The event will be virtual again this year, which will allow people from across the nation to join! We also continue our virtual programs, including our Monday “*Afternoon Conversations*,” our Wednesday evening *Virtual Empowerment Speaker Series* (VES) and our monthly *Golden Girls* sessions. Join us for some camaraderie, conversation and skill building! Learn more at <https://www.thesbrn.org/news-and-events/teleconferences/>.

We would like to give a special shout out to CoWorx Staffing Services, who gave a generous donation through their Janet and Stanley Kane Memorial Day of Giving, to strengthen and fortify our programs. We are so grateful for the many individuals, families and companies that support us!

SBRN has an updated Mission and a new Vision!

As we enter the post-pandemic world, we have used the past several months to evaluate how to best meet the current needs of our community. Our staff and committed volunteers have reflected and evaluated how to move forward with organizational and programmatic changes to address the new reality. We have developed a new mission statement that reflects who we are and what we do as an organization and we created a new vision statement for what we strive to achieve. We look forward to working with you towards a bright future and we continue to be proud to be part of our thriving community!

OUR MISSION



To provide educational resources, social events and advocacy programs that empower people with disabilities and their allies to challenge perceptions, embrace interdependence and live their best lives.

OUR VISION

A thriving community where people with disabilities have equitable access to resources and opportunities to optimize their wellness and realize their unlimited potential.

Time to Go to the Dentist! What to Do to Prepare

With all of the other doctor appointments that you may have, dental appointments may sometimes get pushed to the side, but oral health is critical and shouldn't be ignored. Everyone needs to have regular dental check-ups and some may even need additional work done. It's time to make that appointment.

Although kids and adults with spina bifida are not necessarily at greater risk for dental or oral health problems, there are issues to consider when going to a dental appointment. How to prepare will of course depend on your own situation and health.



What to Consider

Neurogenic Bowel and Bladder - Depending on your needs, you may want to schedule appointments at a particular time of day and you may also want to let the dental office know that you would like shorter appointments. Make sure that you use the restroom before the appointment begins and let the dentist know if you need to take a break in the middle of the appointment. If you have xerostomia (dry mouth), let the dental professionals know so that they can address it.

Arnold-Chiari II Malformation - If you have an Arnold-Chiari II malformation and have issues with dysphagia, aspiration or gag-reflex, you may want to be positioned upright to minimize any issues with airway obstruction and dysphagia. Suctioning during dental procedures is also very important, and you may need an extra staff member to help. If spraying air or water into your mouth is troublesome, ask the doctor to use an alternative method.

Hydrocephalus and Shunts - If you have shunted hydrocephalus, particularly a ventriculoatrial shunt, you may be at greater risk for infections and you may need prophylactic antibiotic premedication for any kind of invasive dental procedures. Discuss with your dentist any other issues you may have with your shunt.



Time to Go to the Dentist! What to Do to Prepare *(continued)*

Limited Sensory Function and Ambulation - If you use a wheelchair, you should work with your dentist to determine whether you would be more safe and comfortable transferring to the dental chair or remaining in your wheelchair. If it is better for you to transfer, there will need to be enough room to do the transfer and the dental chair will need to be lowered enough for you to do so. Also consider whether you will be able to maintain a stable position in the dental chair without slipping down. If you prefer to remain in the wheelchair, you may need to work with the dentist to find adaptive ergonomics so that treatment can take place. Support of your head and neck is essential. If your power chair reclines, then that will be helpful. Wheelchair tilts can sometimes be used for chairs that don't recline.

If you have insensate skin and are at risk for sores and blisters, you may want to use some sort of materials to help you with the hard dental chair. For example, a soft beanbag pillow or some other kind of padding could be used to redistribute pressure points. It also helps to shift your position during the appointment. Remind the dentist or assistants and ask for assistance if needed.

Latex Sensitivity - Even if you don't have a known latex sensitivity, you may want to ask the dental professionals to not use any latex materials. Latex can be found in gloves and masks, nitrous oxide reservoir bags, orthodontic bands/elastics, rubber dams, saliva ejectors and other equipment. Be sure the dental office knows that you need to have non-latex alternatives before you arrive for your appointment. You may also want to schedule your appointment for early in the morning to minimize aerosol exposure.

How to Prepare

- **Accessibility** - When you call to make the appointment, make sure that the office and building are fully accessible. Ask about: parking, elevators, doorways, restrooms and whether there is enough room in the office to fit a wheelchair or transfer.
- **Transferring** - Speak with the dentist in advance whether you will transfer to the dental chair or stay in your own chair. Discuss in detail how either way will be accomplished and what you need to do to prepare.
- **Assistance** - If you think that you might need assistance with transferring or positioning, find out whether extra assistance will be available, or whether you may have someone with you that can accompany and assist you.



Time to Go to the Dentist! What to Do to Prepare *(continued)*

- **Scheduling** - Think about whether you might prefer a shorter visit (if sitting for a long time would be difficult) or a longer visit (if you might need to take breaks.) Be sure to let the office know your preferences. Also think about what time of day works best for you.
- **Premedication** - Discuss with the dentist whether prophylactic antibiotics are needed for your visit.
- **What to Bring** - Be sure to have a list of your medications, as well as information about your shunt or any other condition, like sores or wounds, that may be relevant.



*With adequate preparation and the help of reliable dental professionals,
you will leave your visit with a healthy smile!*

References

Information for this article was based largely on materials from Dr. Faizon Kabani, a leader in dental education, who has written about the dental care of patients with spina bifida:

Kabani, F., "Caring for Patients with Spina Bifida," *Dimensions of Dental Hygiene*, January 2017, <https://dimensionsofdentalhygiene.com/article/caring-patients-with-spina-bifida/>

"Creating Disability-Friendly Dental Practices," *The Independence Center Research Report*, https://www.theindependencecenter.org/wp-content/uploads/2019/07/Creating-Disability-Friendly-Dental-Practices_Final2.pdf

"Dentistry and the Wheelchair-Bound Patient," *DentistryIQ*, <https://www.dentistryiq.com/dental-hygiene/patient-education/article/16356053/dentistry-and-the-wheelchairbound-patient#:~:text=Wheelchair%20tilts%20solve%20the%20daunting%20task%20of%20treating,patient%20and%20wheelchair%2C%20thereby%20eliminating%20possible%20transfer%20injury>

Garg, A. & Revankar, A. "Spina Bifida and Dental Care: Key Clinical Issues," *Journal of the California Dental Association*, 2012, 40(11).

"Spina Bifida and Your Oral Health: How Can Spina Bifida Affect Your Dental Treatment," *Cosmetic Dentistry Guide*, <https://www.cosmeticdentistryguide.co.uk/articles/spina-bifida.html>

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.

● ● ● VIRTUAL
E M P O W E R M E N T
R E T R E A T 2 0 2 1

for adults with disabilities



September 17 - 19

More information will follow soon

<https://www.thesbrn.org/news-and-events/retreat/>

Come Experience SBRN's Empowerment Retreat for Yourself!

In ONE word, how would you describe your 2020 SBRN
Healthcare Hacks experience?



empowering
amazing
fantastic
bomb
bomb.com
family
fun
hackfull
connecting
sobering
spectacular
healthcare
enlightening
awesome
connected
community

The annual **Empowerment Retreat** is a unique, peer-led, fun and interactive three-day conference for adults with disabilities, which is designed to increase independence, socialization, self-esteem and overall growth. Workshops and other activities explore health & wellness, relationships and intimacy, disability justice and other important topics.

Mobile Apps for People with Disabilities

For many of us, our phones have become a major means of communication and a life line to information. Some of it is very helpful, some of it not so much. Apps can be a very useful way to organize your personal information and help you navigate the world. Fortunately, for people with disabilities, many more apps are being developed that can help with coordination, organization and navigation.

We've pulled together a list of apps from online blogs and recommendations, which is in no way complete, but it's a start. We haven't tried them all and can't vouch for how well they work, but they may be worth exploring if they meet your needs.



Health Apps:

- **Spina Bifida Association App** - <https://www.spinabifidaassociation.org/mobile-application/>
The Spina Bifida Association (SBA) developed this mobile app as a tool to track symptoms, medications, bowel management plans and other routines. It can also be used by healthcare providers to access guidelines for care of people with spina bifida.
- **HydroAssist** - <https://www.hydroassoc.org/about-hydroassist-mobile-application/>
HydroAssist was developed to help people with hydrocephalus track their medical treatment history, surgeries, shunt settings and imaging scans.
- **Kids Guide: Using a Catheter** – <https://appadvice.com/app/kids-guide-using-a-catheter/1134737692>
This simple easy-to-use app helps teach kids how to use catheters. It provides educational tips, encouragement, instructions on how to self-cath, and can help create schedules.
- **Wheelchair Calorimeter** - <https://apps.apple.com/us/app/wheelchair-calorimeter/id978183407>
This app uses the GPS location services on your iPhone to help you determine how many calories you burn while exercising in a manual wheelchair. It is designed for outdoor exercise.

Some General Apps for Personal Health Records:

- **Medical Records** - <https://appgrooves.com/android/com.cliniconline/medical-records/medclin>
- **MyKinergy** - <http://kinergycare.com/mykinergy-platform/>
- **GenieMD** - <https://appgrooves.com/app/geniemd-by-geniemd-inc>
- **Apple's Health Records App** - <https://www.apple.com/healthcare/health-records/>

Mobile Apps for People with Disabilities *(continued)*

For Finding Accessible Places and Spaces:

- **The Ability App** - <https://theabilityapp.com/>
With this app, you can find and rate the accessibility of different places, such as stores, restaurants, hotels, parks, theaters or other public spaces, based on different categories, such as mobility, vision, hearing and cognition.
- **Wheelmap** - <https://wheelmap.org/>
Find and mark accessible places all over the world on how wheelchair accessible they are. Anyone can contribute and you can upload images and leave comments. The app can be set in 32 languages.
- **AccessNow** - <https://accessnow.com/>
AccessNow is a community-driven app that pinpoints accessible locations all over the world on an interactive map. You can search for places with specific accessibility features and you can also contribute by providing your own ratings.
- **WheelMate** - <https://www.coloplast.com/products/bladder-bowel/wheelmate/>
This app through Coloplast helps locate wheelchair-friendly accessible parking spots and restrooms worldwide. Users can also rate restrooms and parking areas for cleanliness, convenience, and accessibility.
- **Google Maps** - <https://blog.google/products/maps/wheelchair-accessible-places-google-maps/>
Through Google Maps' street views, users can zoom in on every part of a street to see if the curbs are lowered. Other features are available as well. The new "Accessible Places" feature provides information on accessible entrances, seating, restrooms and parking. In Settings, select "Accessibility," and turn on "Accessible Places."



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