



WYOMING FAMILIES FOR HANDS & VOICES

*"What works for your child is what makes the choice right."*TM

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2020 NATIONAL EDHI CONFERENCE KANSAS CITY, MO

In March several Wyoming EHDl Staff and two Wyoming Parents were able to attend the conference, meet new people and gain new ideas and information!!

HANDS & VOICES UPDATE

Who would have thought that in the spring of 2020 that our lives would be so greatly affected by a world wide pandemic? Social distancing is a phrase we hadn't heard until now. I never would have dreamed that my kids would be doing online schooling from home, that businesses would be shut down, so many people out of jobs, and everyone staying at home. Never once as my kids were growing up did I think they may not get a graduation ceremony and all the other things that make the Senior year special. But here we are taking it one day at a time wondering if and when our lives will return to normal. But with all bad hopefully we are able to find the good and the blessings in the situation. We hope that all of your families are going well.

As of now the Parent Training is still on for June 26 & 27 in Casper. Our insert has the details of the schedule and speakers. We are so excited to have Stephanie and Jody Olson as our Keynote speakers. The kids will also have special visit from Captain America! This year's conference will go until 2:00 pm Saturday, so a pizza lunch will be provided.

Registration is open at www.wyhandsandvoices.org. Additional information about the speakers and topics can also be found on our website.

Depending on the current situation with Covid 19 the official decision to cancel or hold the training will be made the first week in June.

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2020 NATIONAL EHDl CONFERENCE

By Molly McColley, Parent & WYHV Board Member

I was able to attend the EHDl Annual Meeting this year in Kansas City, Missouri. This was my first time attending the EHDl conference and I am grateful to have been given this chance to learn and bring information back to Wyoming Families for Hands & Voices. As a parent attendee, I was excited to find that several of the sessions offered were geared towards parents, both informative and supportive.

I had the privilege to hear Karen Putz speak last year at the Parent Training in Casper and I was excited to see that she was going to be a speaker at the EHDl conference, talking about the Benefits and Downsides of Genetic Testing for Families. My daughter has bilateral moderate hearing loss due to a genetic chromosomal deletion. It is an immensely emotional and life changing choice when it comes to genetic testing, forever changing the path your family travels. Families facing this decision need thoughtful help and support above all else, which can be provided by us as members of Hands & Voices. We can be the caring village that can assist in providing comfort.

I was also eager to learn about the many resources available through the Described and Captioned Media Program (DCMP). Following a simple registration process at <https://dcmp.org/signup>, families and professionals with at least one qualifying student will have access to a large library of online educational videos, never more relevant than the current COVID-19 times we are living in. This service is free to those who meet the requirements.



MACKENZIE NOKES

Mackenzie attends James Verda Elementary in Casper, with the help of a teacher, she made this brochure to share with teachers and coaches. This brochure helps them understand what she needs from them to help her succeed in the classroom and other areas of life. It is a great way for her to advocate for herself.



Questions for Mackenzie

1. Why did you decide to create the brochure?

So my teachers and coaches can know about my hearing aids and what to do

2. How did you decide what to put on the brochure?

My D/HH teacher helped me

3. Are there things you wish you would have included on the brochure, but didn't?

No, nothing

4. Who helped you make the brochure?

Mrs Purdy, My D/HH teacher

Hi, I'm Mackenzie!

I go to Verda James Elementary and I am 10 years old. I'm a hard of hearing girl. I wear 2 hearing aids and I do not need sign language because I use my voice.

I can't hear when it is loud so it is better to hear in quieter places. Also, I can't hear you far away so be closer to me please.

Other things about me are:

I like other sports like gymnastics, basketball, golf and tennis. I absolutely LOVE dogs but sadly I'm allergic



Without my hearing aids....

- I struggle to hear if you aren't close to me.
- When I have a cold or allergies, my nose gets stuffed up and so do my ears. So it is harder to hear.

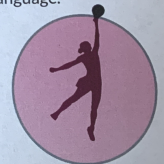
"A loud voice does not equal understanding for me, so please don't yell in front of me."
- Mackenzie, 10 years old

Ways to get my attention:

- If you need me you can use a whistle to get my attention.
- Also you can come up to me and tap me on the shoulder.
- You can wave your hand if you are in front of me.

Ways to communicate with me:

- If you use a whiteboard to show what we are going to be doing it will be easier to understand.
- Also you can still use your voice but maybe wait until it is quieter to talk.
- Fact: I do not know much sign language.



Accommodations I need to be successful:

- Check in with me after the game
- Seat me near the coach
- Show me or model what you want me to do
- Get my attention before giving instructions



For more information, contact:

Sarah Purdy

Teacher of the Deaf

Special Education Services Center

Natrona County School District #1

(307) 253-5483

All About Me!

Tips for working with a deaf kid

Mackenzie Nokes



5. Do you think the brochure has helped others learn about hearing loss and how to communicate with people with hearing loss?

I have only given them to my teacher and two coaches, but it has helped them.

6. Have the people you given the brochure been thankful to have the brochure?

Yes I think so. (From Mom). I think they appreciate the gesture, and the fact that she is sharing the information and bringing attention to her needs.

7. Has it changed or improved the way they communicate with you?

Yeah, in gymnastics they will ask me if I can hear them or if I'm close enough.

8. Is there anything you would like us to know about you?

I'm just a regular kid who happens to wear cool things on my ears!

Finding Family: Building Our Support Network

By Betsy O'Neil, Parent & Guide By Your Side Guide

Hands & Voices has been an incredibly supportive resource for our family since our child, Loren was diagnosed with a hearing loss at about a year old. Hearing loss was his first diagnosis with many more diagnoses to come. While we were searching for additional answers we were embraced whole-heartedly by the deaf and hard of hearing community in our state, including Wyoming Families For Hands & Voices. I think of this community as our first "family" that led the way for us to connect with many more disability communities.

Loren has since been diagnosed with a peroxisomal disorder, which is a rare, genetic, terminal condition that affects all major organ systems of his body. He is on the mild to moderate end of this disorder's spectrum so his decline will be more gradual than someone on the severe end. We've already seen losses in many areas including hearing, vision, motor and cognitive. Loren's hearing will become gradually worse, probably resulting in the need for cochlear implants someday. He will likely never walk on his own and he is slowly going blind.

Once we had his diagnosis we desperately needed more support from families that had experienced what we were going through. Loren's doctors got us in touch with another "family" that has become very important to us - the Global Foundation for Peroxisomal Disorders. The GFPD has many supports for its families including a parent support group on Facebook, an equipment exchange, and a bi-annual family conference.

One of the most devastating aspects of Loren's disorder is his retinal dystrophy in combination with his sensorineural hearing loss. The dual sensory disability of deaf-blindness has been difficult for his father and I to wrap our heads around. We wonder what Loren's life will be like without the ability to hear and see well. We want to give him as many visual experiences as we can now while he still has decent vision. But we know every year will bring additional loss with almost complete loss sometime during his teenage years.

The GFPD family conference was scheduled about six months after we received Loren's diagnosis and we knew we had to find a way to attend. Many of the sessions had a focus on deaf-blindness and would give us insight into what Loren and our family might experience in the future. The conference organizer told us that we may be able to get some funding assistance to attend through our state's Deaf-Blind Project.

The Wyoming Deaf-Blind Project saw how valuable the information about deaf-blindness would be to our family and gave us some financial assistance to attend the conference. Their generosity enabled me to attend with both of my children.

Liam, my oldest at ten years old was able to attend sessions specifically for siblings. Liam learned more about his brother's disorder by attending a deaf-blind simulation and multiple workshops exploring the senses. I attended sessions on deaf-blindness, occupational and physical therapy strategies, equipment needs, IEPs, progression of disease and many other topics specifically tailored to kids with peroxisomal disorders. And Loren spent time in quality care with other kids with his disorder, playing with sensory stimulation toys for deaf-blind children. The best part of the conference though was meeting and learning from other families. We made many lasting connections and hope to go to the next conference to see everyone again and learn even more.

Since attending the conference we have developed even more connections and "families" including the Child Development Center of Natrona County (Loren's preschool), Wyoming Vision Outreach Services and disability support groups in our hometown of Casper, Wyoming. Having a strong support network, both locally, regionally and nationally, has given us a wealth of additional resources, support and hope.

I would encourage all parents of children with disabilities to find your support networks if you haven't already done so. If you need help, your local Hands & Voices group and the Guide By Your Side program can help you make those important connections.



Liam and Loren

There's no
BUDDY
like a brother

coolismart.com

SIMPLE SELF CARE IDEAS

- ENJOY YOUR COFFEE/TEA WHILE IT'S HOT
- START YOUR DAY WITH A MEDITATION
- JOURNAL
- READ A BOOK, UNINTERRUPTED
- WAKE UP BEFORE YOUR CHILDREN TO ENJOY YOUR FAVOURITE SELF CARE PRACTICES IN SILENCE
- GO FOR A WALK
- SPEND TIME IN NATURE
- PRACTICE YOGA OR STRETCH TO START OR END YOUR DAY
- EXERCISE
- WALK OR BIKE TO YOUR NEXT APPOINTMENT
- PHONE A FRIEND WHEN YOU CAN CHAT WITHOUT BEING INTERRUPTED
- ENJOY AN EXTRA LONG SHOWER
- SOAK YOUR FEET
- GIVE YOURSELF A FACE MASK
- CLEAN / ORGANIZE THE SPACES YOU SPEND THE MOST TIME IN
- DE-CLUTTER
- TAKE A BREAK FROM SOCIAL MEDIA
- DO SOMETHING CREATIVE: COLOUR, DRAWING, PHOTOGRAPHY, WHATEVER YOU LOVE
- GET DRESSED & READY LIKE YOU ARE GOING SOMEWHERE, EVEN IF YOU ARE STAYING HOME

WWW.SEWBRIGHTCREATIONS.COM



Wyoming Families for Hands & Voices Contact Information



PO Box 1033
Mountain View, WY 82939
www.WyHandsAndVoices.org



Wendy Hewitt
Executive Director, Parent
307-780-6476
wendy@wyhandsandvoices.org



Mandy Bangerter
Assistant Director, Parent
307-640-0727
mandy@wyhandsandvoices.org



Kim Reimann
GBYS Coordinator, Parent
307-258-0967
kimr@wyhandsandvoices.org

Wyoming Families for Hands & Voices is a non-profit 501(c)3 organization.

TEEN SCENE -

BY RUGER HEWITT

Hi my name is Ruger Hewitt. I live in Mountain View, which is in the Southwest corner of Wyoming. I am a Senior at Mountain View High School. I am the only boy in the family stuck between two girls. Of course they have always loved to torture me. My older sister, Dallie has really good hearing, but my younger sister, Kassidy and I were born with bilateral sensorineural hearing loss. It is genetic, so we can thank our parents for that. I received hearing aids at 3 months, my first cochlear implant at 18 months and my second one when I was seven. Kassidy also wore aids for her first year and later received implants. The implants allow me to hear many things that I wouldn't have been able to otherwise. I can also take them off and sleep very soundly and ignore my sisters. Dallie would complain that our dogs' barking would keep her up at night and I would brag about sleeping right through it. Over the last few years I have had struggles and frustration with my right implant and my audiologist realized that my internal device had been recalled and was failing. So I had a revision surgery in the spring of my sophomore year, and it has never worked as well as the one before, which has been very frustrating for me, my mom and my audiologist. So I will be getting another revision surgery this coming summer and hopefully it will work better.

As early as they could sign me up, my parents had us involved in all kinds of activities. I was involved in baseball, basketball, wrestling, football and soccer for a lot of years. In middle school I did rodeo, basketball, wrestling, and football. By high school I did two years of basketball and then focused on rodeo. With all of the many things I have been involved in we had to figure out a way to keep my implants on under football helmet, wrestling head gear, cowboy hats, and to stay on when I was running down any court or field. This sometimes involved headbands and sometimes tape. When I have struggles with this I call my mom, she is full of advice.

We grew up on a small ranch just outside of town. We have always had horses and dogs. When I turned eight and was old enough to do 4-H, we became very involved in showing pigs and doing the horse show. Then we became very involved in rodeo. We started doing local rodeos, then high school rodeo and now lots of rodeos and jackpots. I love tie down roping and team roping. I have had a lot of fun and have made many memories and life long friends. I hate to even guess how much my money my parents have put into rodeos for us kids.

I am a part of the Senior class that has been home schooled since March. Over the years I have told my mom she should home school me, but after this I am glad she didn't. I miss my friends and the social part of school. Our high school is doing every thing they can to have some kind of Graduation Ceremony, so we wait wondering what that might be. We will know within the next couple weeks. Throughout my life I have realized that you have to work hard for the things you want. I have also learned that you have to accept the things you can't change. I am sad for the parts of my senior year that I have missed out on, but I know that this pandemic is out of my control and I just have to accept it and make the best of it. Following my summer surgery I plan to serve a church mission and when I return, I plan on getting a Machining and Business Technology degree at Bridgerland Technical College in Logan Utah.



Here's to the Class of
2020 and the things they
missed out on their
Senior year. Stay Strong!



Nugget- our horse also
smiled for the camera!

