



WHERE DIFFERENCE DOES NOT EQUAL DISABILITY

## Teen Camp Returns!



### Pathfinders!

Shari & Jerelyne here! We are reaching out to say that we are so excited for Teen Camp this year! We had so much fun with you all last year, but it's been over three years since we've had our own exclusive time together. There is just something special about having Camp to ourselves for a night!

We have a great group of you registered for Teen Camp this year and so we have more fun activities planned for you all! We've got the following in store as weather permits: water activities, night hiking, stargazing, snacking, big game night! \*If you have any board games you really enjoy and want to share, please bring them with you!

The theme for camp this year is "This is My Story." In working with this theme, we are planning a social media takeover! We want to share ideas and stories with each other and the rest of Camp. Sharing your story with the group is optional but encouraged, so we hope to create a fun way to do so! One prompt is to "Write your story in six words." These can be shared at our Teen Camp experience and/or as a feature in the H2L Newsletter.

Please reach out to Shari Gorman with any questions, concerns, or suggestions for Teen Camp at [gormancrew@yahoo.com](mailto:gormancrew@yahoo.com)

## HAND CAMP IS COMING!

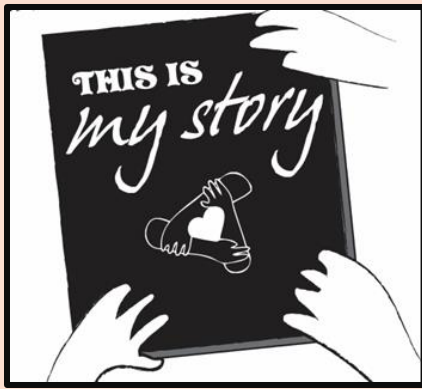
April 12 -14, 2024



NOW OPEN!

**VOLUNTEER APPLICATIONS**

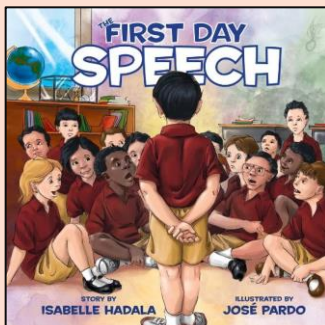
[Click here to register as a volunteer.](#)



## BY IZZY HADALA, HAND CAMP GRAD AND AULD

I'm 25 years old living in the Orlando area and I work in finance. I'm a published author, MBA graduate, fiancé, daughter and big sister who loves music, traveling and binge watching old tv shows. I'm also limb different. I was born with a rare genetic condition called ectrodactyly ectodermal dysplasia, causing teeth, hands and feet to not develop fully, among other things.

I started attending hands to love in its first year as a one year old and grew up attending Hand Camp. It helped me build my confidence and learn to embrace who I am. I've had the privilege to be a part of a community and have had the honor of hearing many people's stories. These stories shaped me, reminding me that even if things were hard, it was something that I could work through, and I had the support of others why had gone through similar things too.



When I wrote my book and became a motivational speaker, it was my turn to share my story. I spoke about self-acceptance and self-love at a time where my differences and medical problems made it difficult to love myself. I was awaiting major surgery and facing bullying at school, but I never felt that I could share that part of my story because it was hard to talk about.

As an adult, I'm coming to terms with all the aspects of my story, and I proudly share it so that others don't feel alone as they navigate similar situations. When we can share our story authentically, it allows for genuine connections with others to help them on their journey, just as so many have done for me. As I start this next chapter of getting married and continuing in my career, I'm excited for what the future has to offer.



Hands to Love is a 501(c)(3) non-profit organization. We strive to provide all Hands to Love events and activities at the lowest possible cost to our special families. These services are available with thanks to the generous support of our donors, like you! Thank you for helping us make a difference in the lives of the families we serve. To give, please click [HERE](#).



# LIKE ME

BY SAVANNAH GRANNAN



Since I was two years old, my parents have been signing me up for Hand Camp: A place for people like me. There's always such a *feeling* when the words "like me" are used. Because it means I'm different. And different means you're not normal. And the world is often cruel to abnormalities.

But I never quite understood it. I wasn't anything special. Why would people be shocked to see me tying my shoes when I have routinely interacted with people who scale rock walls and shoot bullseyes without any arms?

I became so used to seeing success with disabilities that I couldn't see why going to this camp was so important. But, last spring, I got it.

I was able to watch a little girl with one arm perform a ballet scene, and another girl gasp loud enough to ring over the crowd. I could see the tears of excitement in her eyes because, for the first time, she was seeing someone *like her* perform on a stage in front of so many people without a care. And in that moment I realized what an enormous blessing this camp has been to me throughout my life.

I've never had to face the feelings of isolation that scholars insist come with my amputation because Hand Camp has been an organization that has prepared and protected me from that type of pain before it had a chance to reach me.

After I graduate high school, my goal is to become a counselor at Hand Camp so that I can become someone else's "like me," and I am certain nothing can compare to the honor it will bring me.



*If you have contributions or ideas for future newsletters, please contact Amy McClelland, Newsletter Editor, at [amy@handstolove.org](mailto:amy@handstolove.org)*

# H2L INNOVATION STATION

by Laura Faye Clubok, MS, OTR/L  
*On The Other Hand Therapy*  
 Columbus, Ohio



## Laptop Use

This month, we begin discussing everything related to laptops. While there is now a body of research on children using computers, unfortunately I am not aware of research specifically on computer use and adaptations for children with ULD. So, what follows are recommendations based on my personal experience, the experience of families and adults with whom I've worked, and research involving typically developing children. The most important principle when choosing technology for your child is: **as much as possible, adapt the technology to the child, not the other way around.**

Because upper limb differences can be so varied there is, unfortunately, no “one-size-fits-all” recommendation. Because most children these days use laptops much more often than desktop computers, we will focus on laptops. Still, much of the following also applies to home desktop use, which has the advantage of being more configurable.

### Mouse Options

The mouse is a built-in controller for the cursor. On laptops, these are often called the touchpad or trackpad. Research on typically developing children using laptops in schools suggests that an external mouse is ergonomically preferable to the trackpad on a laptop; however, historically computer mice haven't had optimal biomechanical design, so frequent mouse use still can lead to strain and pain as people age. It is important to be mindful of how children with ULDs use their dominant hand, whether or not that hand has a limb difference, because of the additional wear and tear on that limb. If at any point, your child develops overuse pain or strain on either side, it is important to take it seriously and pursue treatment (read about [Overuse Syndrome](#)).

- Research has shown that, having acclimated to using a regular mouse, many people later are resistant to switching to an adaptive mouse. Depending on your child's hands, there are multiple potential options worth considering for an **external mouse**, (such as a small elec Space Mini Small Wireless Mouse designed for children 3-7) or **vertical mouse** (Logitech Lift Vertical Ergonomic Mouse is designed for smaller hands) or **trackball** (Kensington or Logitech). While there are few adaptive mouse options specifically designed for children, some do have smaller versions. In order to prevent strain to your child's arms/hands, it may be worth the hassle of potentially purchasing (and possibly returning) several mice to find a good match for your child's hand size, range of motion, and personal preference. It also may be worth trying to find two comfortable mice - one for home and one for school, to alternate muscle usage in your child's hands. Also note that schools are generally responsible for providing an appropriate computer mouse for any limb different child with an IEP or 504 document.
- Some children with ULD might benefit from using the [Microsoft Adaptive Accessories](#), which is a family of customizable input devices. One of the options is the [Microsoft Adaptive Mouse](#), for which several [free 3D printed designs](#) are available

Future columns will discuss other laptop factors such as carrying the laptop, computer setup, keyboards, laptop weight, learning touch typing, and touch screen options.

ontheotherhandtherapy



**CONGENITAL UNILATERAL**  
upper limb  
difference  
impact study

**PLEASE COMPLETE SURVEY**

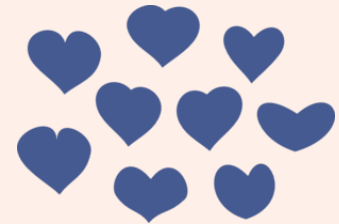


### Congenital Unilateral Upper Limb Difference (CUULD)

**Impact Study:** Adults 18+ with a Congenital Unilateral Upper Limb Difference (CUULD) are invited to participate in the CUULD Impact Study at <https://forms.office.com/r/NahpE4iZga>. Amber Jenkins, an Assistant Professor of Occupational Therapy at Rockhurst University, also has a congenital unilateral upper limb difference, and is studying the lived experience of individuals 18+ with CUULD. Amber's research goal is to provide additional resources to our population AND to the therapists and doctors who work with us. While there is a good amount of high-quality research on people with acquired limb loss, there currently is almost no research on people with CUULD. The survey takes only 5-10 minutes to complete. You can [learn more](#) about the survey.



## What we love about



*I love that our son was able to meet friends like him and that we have built lifetime friends with other parents and families. (Lacye Mills)*

*I love the family I have in Hand Camp!!! (Christa Goodwin-Whitten)*

*Three days of relief from advocating and educating! For these magical days, my son isn't unique for having a small hand. He gets to be special in other ways. (Amy Heisel)*

*H2L helps my son to see how special and important he is. (Caitlin Rigamoto)*

*I love the way H2L embraces families and helps them help their limb different kiddos. I love how much Hand Camp bolsters our kiddos self-esteem. I love the feeling that we are one big family. I love the friendships that pick up after a year apart as if no time has passed. I love the people who do all they can to make Hand Camp an awesome and amazing time for our families. Y'all are the best! Can't wait to see you all in April! (Alycia Apostolides)*

*The support between parents, and the way the campers interact. (Tom Stephan)*



### H2L Online Boutique

Click [HERE](#) to order your H2L swag!

10% off all orders pre-camp!

Proceeds from all sales go to Registration and Travel Scholarships!

