

# Medically Complex Program



## We Need Your Help!

Interested in learning more about The Nemasket Group's Medically Complex Program? Join us on June 15<sup>th</sup> at 5:00 p.m. for a roundtable discussion on a variety of topics including how we can help you and your family. We have received feedback from our families regarding your previous provider Bamsi and what they did or didn't do. We want to know how we can service your needs better and would appreciate your attendance.

Please RSVP with [ShanellStewart@nemasketgroup.org](mailto:ShanellStewart@nemasketgroup.org) for the Zoom link invitation.

## We are looking for ideas!

What can we do as The Medically Complex Program that would help you in your journey? Would you be interested in a support group or even a cookout/ ice cream social to get together with parents with similar situations? We all know we learn more from other families than anywhere else. Maybe you don't have a sitter and want to do something virtual (i.e. adult or family paint night). Please let me know so we can plan for these events.

Email [Shanellstewart@nemasketgroup.org](mailto:Shanellstewart@nemasketgroup.org)

### Medically Complex Program at The Nemasket Group

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# **500 CEOs Commit To Prioritizing Disability Inclusion**

<https://www.disabilityscoop.com/2021/05/19/500-ceos-commit-to-prioritizing-disability-inclusion/29347/>

by Shaun Heasley | May 19, 2021

The chief executives of Apple, Google, Coca-Cola, Procter & Gamble, Sony and hundreds of other international organizations are committing to advance disability inclusion. The companies are part of a group known as The Valuable 500 that first formed at the 2019 World Economic Forum Annual Meeting in Davos, Switzerland in an effort to improve life for people with disabilities.

Now, the collaborative says it has reached its goal of signing on 500 members, which collectively represent over \$8 trillion in annual revenue and more than 20 million employees globally.

Each organization has made a public pledge to promote disability inclusion in one way or another. Some companies have appointed advisory boards or launched advertising campaigns featuring people with disabilities, while others like Tommy Hilfiger and Ugg have developed adaptive products and companies like Unilever and Auto Trader have enhanced employment opportunities.

As part of a second phase of the group's efforts, those behind The Valuable 500 said 13 member companies will work together to facilitate a jobs portal made by people with disabilities, conduct a brand audit to learn more about consumers with disabilities and promote accessibility skills in upcoming technology professionals, among other efforts.

"There is plenty more business leaders globally can and must do to better serve the 1.3 billion people worldwide with disabilities," said Paul Polman, chairman of The Valuable 500 and a former CEO of Unilever. "The commitments made by the 500 global companies over the course of the last two years have already made a tangible difference, and I greatly look forward to playing a role in activating this network and accelerating disability inclusion worldwide."

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## **Raising a Medically-Complex Child**

<https://handtohold.org/raising-a-medically-complex-child/>



There are more than 6,000 rare diseases in the world, and approximately 1 in 2,000 people have been diagnosed with one. Every person and/or family affected by rare disease is different in their own way, but we all share the same problem: we are "rare" and often even the medical community doesn't know what to make of our diagnosis.

My 11-year old, Mighty Z, is affected with a rare disease that affects only 800 children worldwide. Her disease does not discriminate on the basis of race, or gender, and it is known by two different names: Ondine's Curse (its first and oldest name) and Congenital Central Hypoventilation Syndrome or "CCHS" (its modern name). CCHS is a central nervous system disorder in which the autonomic (involuntary) control of breathing is low. For Mighty Z and other CCHS patients, this means that the respiratory response to oxygen and carbon dioxide is sluggish at best during the day; and, it is absent at night, when sick and/or when stressed.

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There is often (but not always) a gene mutation component to CCHS. The PHOX2B gene provides instructions for making a protein that acts early in development to help promote the formation of nerve cells (neurons) and regulate the process by which the neurons mature to carry out specific functions (differentiation). The protein is active in the neural crest, which is a group of cells in the early embryo that give rise to many tissues and organs. Neural crest cells migrate to form parts of the autonomic nervous system, many tissues in the face and skull, and other tissue and cell types. The PHOX2B mutation associated with CCHS adds extra alanines to the polyalanine tracts in the PHOX2B protein. This type of mutation is called a polyalanine repeat expansion.

If someone has the PHOX2B mutation their CCHS diagnosis is clear. Unfortunately, absence of the mutation does not necessarily rule out CCHS – if a patient's symptoms look like and act like CCHS, the diagnosis can be made even though the PHOX2B gene tests normal.

Because of CCHS, life is in many ways altered for Mighty Z. As a baby she was trached and ventilated 24-hours a day until I could teach (sprint) her to breathe off the ventilator at night. Sprinting is a very tedious process, and sometimes it was literally two steps forward, and then three steps back. There were times when I felt like throwing in the towel and giving up, but then I would look at my beautiful little girl and just know that I could never give up. Mighty Z is a fighter, and I had to be one as well. After many long battles, we finally won the war. In our case, winning the war meant that when she was 2-years old, we were able to get Mighty Z to where she was ventilator-dependent only 12-hours/day.

As you might well expect, Mighty Z's milestones were delayed. On top of teaching her to breathe via the sprint method, I also had to teach her to hold her bottle, roll over, feed herself, crawl, walk and talk. Each small success was huge in my eyes, and it was hard to make others understand why I was so excited that Mighty Z was finally able to do what their children did naturally. I feel that as parents of medically-complex children, we all understand the joyous feeling of these small accomplishments. As I have walked down this road as a special needs mother, I have found that until you know the deepest pain, you can never really know the deepest joy.

At 11-years old, Mighty Z is still dependent on her machines 12-hours a day. She feels that she is normal and even typical, and she does not see herself as being different than any other child. Mighty Z knows that she has a disease, and at night I have to "plug" her in, but as she sees it, everybody has "issues," and CCHS is just her issue. I often marvel how that she can just accept this disease and move on, when at times I need to pull myself off the floor.

Every couple of months, we grace the doors of specialist after specialist, as doctor office visits are just part and parcel of caring of taking care of Mighty Z. She has gone to school with IV's and heart monitors, and she has missed birthday parties she wanted to attend because she needs a scan, test, treatment and/or some other such medical procedure. Through it all, Mighty Z is a testament to fortitude and grace as she undergoes these pokes and prods, and she is always the one with a smile on her face and a ready hug for those who are in need.

Mighty Z goes to a regular mainstream private school, and she thrives there. She has many friends, and she is always sought after at lunch and at recess to play. She plays the piano beautifully, and she sings in the school choir. In short, Mighty Z lives a very full and rich life. Though I suspect we have to more frequently rush her to the ER and that we spend more of our vacation time in the PICU than do most families, this is our "normal", and to us it isn't such a big deal. Many dinner parties have been cut short simply because Mighty Z was falling asleep – and for us, that means that particular party is over. Early-nights because of CCHS notwithstanding, there isn't an ounce of quit in Mighty Z – as long as that is the case, there won't be an ounce of quit in us, either.

# 5 Simple Ways To Support Disability Activism

By Andrew Pulrang | May 15, 2021



Disability activism is empowering.

For some disabled people who get involved, it opens up avenues for friendship and "chosen family" among other disabled people that they may have missed all of their lives. In some circles at least, disability activists are admired. Activism can be a strong source of pride. Disability activism is also useful. It makes real positive change.

But not everyone can become a full-time activist, or even a part-time advocate for more than an occasional personal need. There can be many reasons for this: Effective activism takes time and effort to learn, and calls for personal sacrifice of time, energy, and resources that many disabled people and their allies just don't have.

Some disability activism activities are still -- unfortunately and shamefully -- inaccessible to some disabled people. Some people have personalities that are well suited to activism, while others don't. Some people enjoy activism and are naturally good at it. Many are not.

Modern social justice activism, including disability activism, often seems intimidating, even scary. People are worried they don't know enough, or are afraid of being publicly humiliated for "mistakes" they might make and people they might offend.

But none of these are enough reason to shun disability activism entirely, if its goals are your goals. There are ways to help that don't require full-on commitment or a wholesale change in your life and personality.

## PROMOTED

### 1. Share disability articles and action alerts on your social media platforms

This is especially helpful if you have "friends" and "followers" from other professions and communities, who don't spend much time with disability issues. Your credibility with them may prompt at least a few of them to read and think about disability issue for the first time, or from a new perspective.

#### Examples:

Share an article to your Facebook page explaining why the Biden Administration included home care in its infrastructure plan. Tweet about why current voting rights debates matter to you as a disabled person. Post a creative and compelling disability rights meme to Instagram.

### 2. Amplify the voices and work of disabled activists

Social media in particular has built-in ways for you to boost what other people are saying and doing.

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Boosting other people's work and ideas is a valid and valuable way to contribute to disability issue discussions, especially if you don't yet feel comfortable explaining things in your own words.

It's also a way to "pass the mic" to others who struggle to be heard, but have something valuable to say. Non-disabled allies and disability activists especially should make it a priority to share the words and work of activists who have disabilities themselves.

Examples:

If you aren't sure how to express your own views on especially contentious issues -- like disability and racism, conflicting interpretations of autism, or different takes on the "right" terms to use for disability -- you can share or retweet things other people have said that you like or think are interesting.

When you feel passionately as a non-disabled parent about bullying of disabled kids in schools, or funding for disability support services, try sharing and endorsing what disabled people themselves are saying and doing, before giving your own take.

Social media isn't the only place to do this. You can also center disabled activists' work in conversations, presentations, and your own writing. Just remember to cite them properly. Social media essentially does for you. So offline, you must be careful not to imply that someone else's words and ideas are your own.

### 3. Tell your own disability story

This is often the best way to start having your own say. Begin by explaining exactly how a disability issue affects you as a disabled person, or as an ally to a disabled person. If you are a non-disabled ally though, like a parent or spouse, make sure not to confuse your story with your disabled loved one's own story. They may be related, but they aren't the same. You can only really tell your story from your point of view.

Also, don't stop with your story. If your goal is some kind of concrete change, don't just tell your story to make people feel bad for you, or to center your own struggle only. Whenever possible, draw clear connections between your personal situation and a broader disability issue, how it affects other disabled people, and actions your audience can take to address the issue.

Examples:

Describe in detail how home care works for you, or how your life would improve with home care, and ask people to support home care funding.

Explain your concern as a parent of a disabled child about problems in your child's schooling, and ask people to support better funding of support services, or enforcement of the [Individuals with Disabilities Education Act](#).

Again, don't speak for a disabled child, spouse, or other family member, even if they don't have readily available means to speak for themselves. Tell your story, and how it includes them. Advocate with them, not for them. That may seem like a small distinction, but in the long run it means a lot.

### 4. Connect advocacy for yourself or a loved one with a disability, and activism for the broader disability community. It can be useful to think of this by calling the persuasion work you do to solve

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your own disability-related needs and conflicts "advocacy," and work with others on broader disability policies and practices "activism."

Both advocacy and activism are important and have their place. But their goals, methods, and tactics are often quite different. And carefully-chosen activism has enormous potential to expand the scope and positive impact of effective advocacy, beyond yourself or your family alone.

Examples:

As you advocate for accessibility at a restaurant you would like to dine at but can't, pay attention to local enforcement of all accessibility codes, and what's happening nationally on enforcement and defense of the [Americans with Disabilities Act](#).

After going through a few of your own advocacy battles with an employer, you may find yourself well equipped for some activism on employment discrimination laws and disability accommodation practices in workplaces. If you have found some measure of success in a number of difficult areas of living with disabilities, look for ways to support other disabled people, and improve the conditions they will have to face in the future.

#### 5. Remember disability issues when you vote

Disabled people have been [voting in greater numbers in recent years](#). But disabled people on average still register and vote at lower rates than non-disabled people. And it is still hard to pin down whether there is a coherent "disability vote," with identifiable, predictable points of view. That's partly because it's not clear how much disabled people factor in their disability experiences when they do vote.

You don't have to make disability your top political priority to make a difference with your ballot. You don't have to set aside all of your deepest opinions. You don't have to put your disability in charge of your vote. But it makes sense to at least find out where candidates stand on disability issues that will affect your life or the lives of disabled people you care about. That means insisting that candidates take the time to develop meaningful positions on disability issues.

Examples:

Whether online, in-person, or both, takes every opportunity to ask candidates who will be on your ballot about disability issues you care about most. Ask about national issues like Social Security and disability rights laws, state issues like home care funding, and local issues like street, sidewalk, and public building accessibility. Give candidate's stands on disability issues equal standing in your thinking to more mainstream issues like national defense, civil liberties, and domestic spending. Realize that issues important to you as a disabled voter may be important to all voters, whether they realize it or not.

These tips are meant to be simple, though not necessarily easy. At least some of them are accessible to just about anyone, regardless of experience or expert knowledge.

One of the keys to getting started is resolving not to center yourself from the outset. Be willing to share the stage and be a voice in a chorus. It truly can be as important and rewarding in disability activism to work behind the scenes as it is to be a lead actor or soloist.

# FREE Estate Planning for Special Needs



Webinar with a Massachusetts' based special-needs law firm.

June 1st, 2021

10 a.m.

Free. Learn why some wills do not work, even when drafted correctly, the necessary steps to protect your home from future nursing home expenses, and how to reduce estate death taxes.

## Topics include:

- How to protect your property, and reduce estate taxes
- Why up-to-date health care proxies and powers of attorney are now crucial
- How the new SECURE Act (of December 2019) can impact your estate planning
- Why a HIPAA release is essential in obtaining medical information
- How to keep your family out of probate
- How to obtain a free virtual estate planning meeting

Once you register, you will receive an email with simple instructions for connecting to the webinar.

\* The speaker will be Tax Attorney Michael T. Lahti.

To RSVP or for more information visit [www.fletchertilton.com/seminars-events](http://www.fletchertilton.com/seminars-events) or contact 508.459.8000

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## Epilepsy Support: Seizure First Aid & Recognition



Webinar with the Epilepsy Foundation New England.

June 24th, 2021

To RSVP or for more information, visit

<https://epilepsynewengland.org/events> and scroll down to your desired event, or contact 617-506-6041 or email [info@epilepsynewengland.org](mailto:info@epilepsynewengland.org).

Do you know someone with epilepsy? Would you know what to do if they had a seizure with you?

- ❖ This is a one hour, online class.
- ❖ Learn about different types of seizures and what to do to help and keep someone safe.

Epilepsy Foundation New England is a 501 c 3 nonprofit organization whose mission is to help people and families affected by epilepsy in New England. They serve the Maine, Massachusetts, New Hampshire, and Rhode Island communities affected by epilepsy.

# Sensory-Friendly Sundays



Attleboro, Everett, Lowell, Methuen, Dartmouth, N Dartmouth, Worcester, MA.

The first Sunday of each month. Activities & Play Place for Children with Autism & Special Needs.

For more information and Massachusetts' locations updates, visit [www.chuckecheese.com/events/sensory-sensitive-sundays/](http://www.chuckecheese.com/events/sensory-sensitive-sundays/) or contact [memories@cecentertainment.com](mailto:memories@cecentertainment.com)

- ❖ For families who have children with autism and other special needs. Chuck E. Cheese Sensory events include a trained staff that work to ensure each guest has an enjoyable visit, with the knowledge that a visit can be very stimulating for any child, and creating an event for all kids.
  - ❖ Starting in May 2021, participating locations will open 2 hours early on the first Sunday of the month to offer a sensitive-friendly experience for the remainder of the year.
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## 21 Shades Family Support On-Line Group with Massachusetts' Down Syndrome Congress



**Virtual Group**  
June 10th, 2021  
7 pm.

A state-wide African American / Black Family parent and caregiver Support Group for those with a family member with Down syndrome.

This is an invitation only group.

- ❖ Monthly calls and social events; Open to all family members.
- ❖ To support the community during COVID-19, the family support team is now actively supporting families virtually and has many online support groups now forming.

To request an invitation to this on-line event, contact Melissa 617-416-5240 or Terri 347-882-9694

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## Summer Steam Program

Social Development. Skill Building. Self-Expression.  
Experience the world differently.

Express yourself through art and science.

Monday – Friday 11 am & 2 pm  
July 12 – August 20, 2021

Contact Sara Rodrigues  
[info@balancedlearningcenter.com](mailto:info@balancedlearningcenter.com) or visit <https://forms.gle/kPLrcA34J8PWgudu5>