

**Dysautonomia**

Dis – oughta – know' – me – uh

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**DYSAUTONOMIA AWARENESS**

BERNADETTE CAMPOS RN

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**What is Dysautonomia?**

It is a dysfunction of the autonomic nervous system (ANS).

Controls our automatic functions: heart rate, blood pressure, digestion, kidney function and temperature.

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**Who is affected by it?**

- Dysautonomia affects more than 70 million people worldwide who live with different forms of dysautonomia.
- There are about 15 kinds and 3 main types.
- Women are five times more likely to have dysautonomia than men.
- In some cases, there is a genetic component.

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**3 Main Types**

- Neurocardiogenic syncope (NCS): most common (from mild to severe).
- POTS: Postural Orthostatic Tachycardia Syndrome: Affects 1/100 teenagers. No two people with POTS are the same.
- Multiple System Atrophy: MSA (rare): affecting people of age 40 and up; degenerative disorder similar to Parkinson's: People usually become bedridden 2 years after diagnosis and have a 5-to-10-year lifespan.

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**Some of the most common Signs and Symptoms**

|                          |                         |                          |
|--------------------------|-------------------------|--------------------------|
| Lightheadedness          | Tachycardia             | Fatigue (extreme)        |
| flight or fight response | Chest pain              | Fainting: venous pulling |
| SOB                      | Temperature sensitivity | GI upset                 |

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**Prognosis**

- There is no cure for dysautonomia / POTS
- Symptoms become more manageable over time and sometimes disappear as the person gets older.
- Usually, people that have POTS or other types of dysautonomia have a team of doctors: cardiologist, nutritionist, neurologist etc.

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**Awareness**

Most dysautonomia's /POTS are undiagnosed or misdiagnosed they are often confused by a panic attack or anxiety disturbances.

It is considered an invisible illness because the person often "looks fine" and nurses, doctors, and even parents think the person is often making things up.

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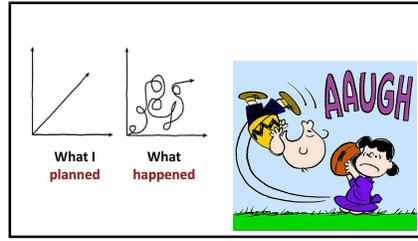
**Invisible Illness**

Alice & Alysso Quiroz

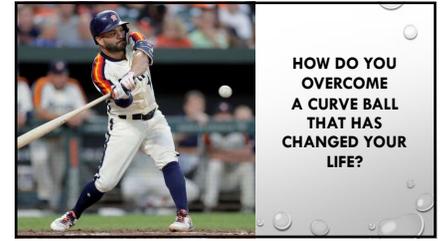
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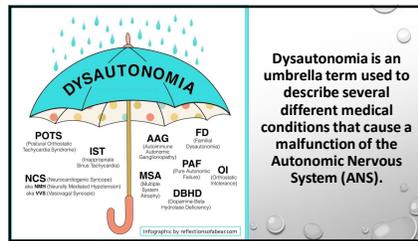
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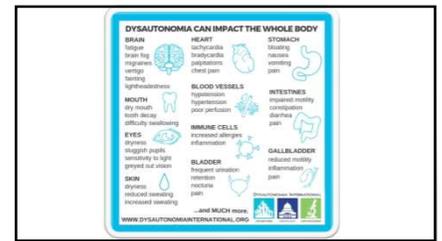
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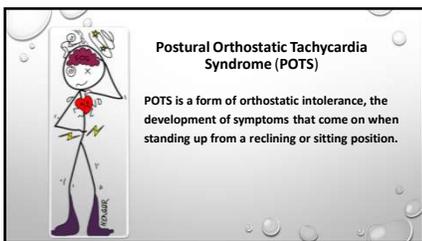
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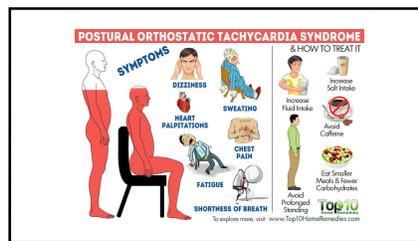
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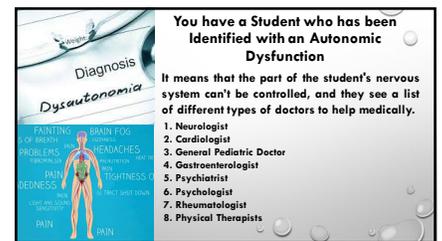
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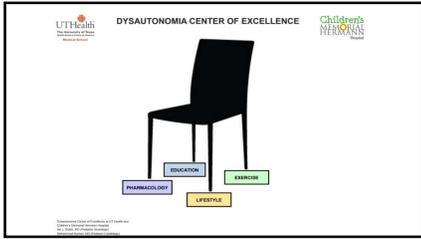
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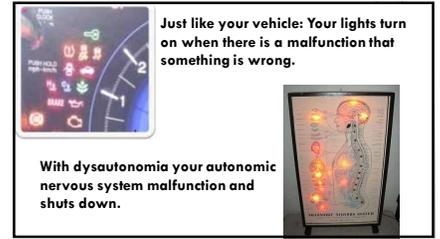
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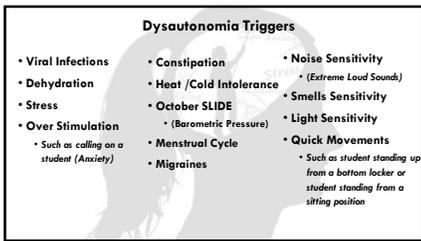
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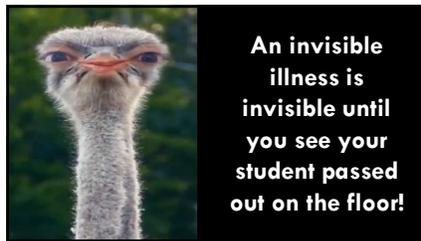
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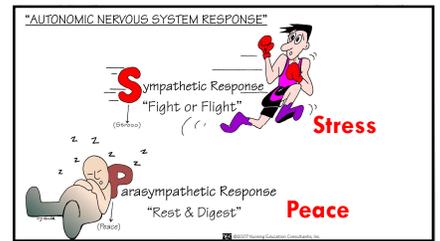
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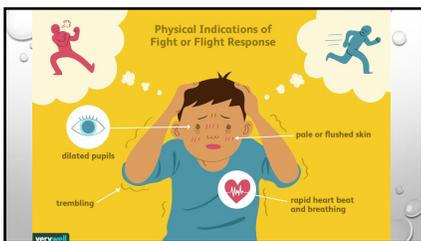
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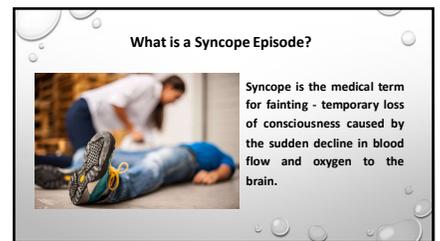
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**If a Student has a Syncope Episode?**



- Lay the student flat on their back.**
  - Elevate the student's legs above the level of their heart, to restore blood flow to the brain.
  - Loosen tight clothing.
  - If in layers, then remove layers
- Open the student's eye lid, tap lightly and talk to student until they wake up.**
  - If the student doesn't respond, call 911 immediately!
  - Contact your school nurse and stay with the student until he/she is fully recovered and alert.



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Your student and their family have been through many stages dealing with this illness.




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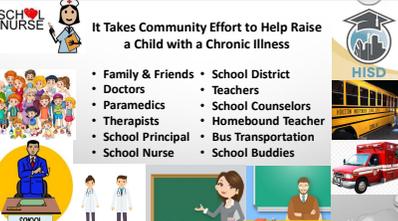


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**SCHOOL NURSE**

**It Takes Community Effort to Help Raise a Child with a Chronic Illness**

- Family & Friends
- Doctors
- Paramedics
- Therapists
- School Principal
- School Nurse
- School District
- Teachers
- School Counselors
- Homebound Teacher
- Bus Transportation
- School Buddies



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On a road trip, you will need a navigation system to help you travel from Point A to Point B.

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**Navigation System / IEP**

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**Admission Review Dismissal Committee (ARD)**

- ARD Meeting** – A committee of people who determine whether or not a student is eligible for an IEP for eligible students. (Parents and student are part of the committee)
- Evaluation** – Parents must provide written consent
- IEP** – Individual Education Plan
- IHP** – Individual Health Plan (Nurse's section)
- Accommodations** to meet the student's individual needs

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### What's the Criteria for Eligibility as a Student with Other Health Impairment (OHI)?

- **Your student has been medically diagnosed by a doctor.**
- SEC. 300.8 Child with a Disability
- Other health impairment is a disability category included in The Individuals with Disabilities Education Act (IDEA).
- Under IDEA, a child who has an "other health impairment" is eligible for special services to help the child address his or her educational, developmental, and functional needs resulting from the disability.



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### What's the Criteria for Eligibility for a Student with Other Health Impairment (OHI)?

|  |  |
|--|--|
|  <p><b>34 CFR §300.8 Child with a Disability</b></p> <p>Other health impairment means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that— (i) is due to chronic or acute health problems and (ii) adversely affects a child's educational performance.</p> |  <p><b>19 TAC §89.1040, Eligibility Criteria</b></p> <p>Other health impairment is one who has been determined to meet the criteria for other health impairment due to <b>chronic or acute health problems</b> as stated in 34 CFR, §300.8(c)(9). The multidisciplinary team that collects or reviews evaluation data in connection with the determination of a student's eligibility based on other health impairment must include a licensed physician.</p> |
|--|--|

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### National Network

- The Americans with Disabilities Act (ADA) became law in 1990. The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.
- Students must be provided a **Free and Appropriate Public Education (FAPE)** in the **Least Restrictive Environment (LRE)** to the greatest extent possible with their non-disable peers.

|  |                                     |
|--|-------------------------------------|
| <b>Least Restrictive Environment (LRE)</b> | <b>Most Restrictive Environment</b> |
| School                                     | Home or Hospital Bound              |

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### An (IHP) Individualized Healthcare Plan Will Support a Student's Individual Needs

- The IEP section of the PLAAFP, Present Level Of Academic Achievement and Functional Performance, **page mark the corresponding box under "health needs"**.
- Reference the location of the IHP in the "other information essential for the development of this IEP" section of the PLAAFP.



**Accommodations**

- Absences are expected with this condition, due to symptoms or doctors' appointments. **The student should not be penalized for these absences.**
- Have teachers keep a folder in each classroom: this allows the student easy access to handouts and homework.
- Teachers should coordinate how much homework is given. Avoid overloading the student.
- Intermittent Homebound may also be utilized.**

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**Accommodations**

- Carry cell phone at all times
- Student will pick an assigned buddy
- Allow extra time in between classes to change classrooms with a buddy
- Elevator pass (taking the stairs may not always be safe due to dizziness and fatigue)

**CAUTION  
DO NOT  
USE STAIRS**

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**Accommodations  
Bottom Locker vs Top Locker**

- The quick movement from standing up quickly could lead to a syncopal episode. To avoid the student from passing out, it is best to assign a top locker.
- An extra set of books should be provided for home. Due to lugging heavy books around it can be very tiring.

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**Fire Drills or Intruder Drills**  
Drills may cause a fight or flight response.

**Practice Fire Drills** – Notify student prior to monthly fire drills: *Student will prepare to use sunglasses & ear plugs or call parent for early pick up.*

- Sunglasses:** helps with light sensitivity due to flashing strobe lights.
- Ear plugs** – helps reduce the noise and muffles the painful sounds due to noise sensitivity.



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**Unexpected Moments**

Having to sit on the floor in the most unexpected places, can be embarrassing for a student with an invisible illness. But can also be helpful and vital to the student's safety.

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**Migraines**

Migraines can be so severe where a student can not function.

- Migraines can be a trigger by the sensitivity to the blue light from cell phones and computers.
- Changing the blue light brightness on computer screens and cell phones can help.



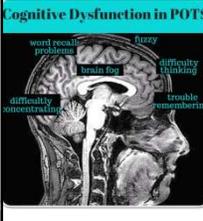

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**Seizure First Aid Toolbox**

- STAY** with the person until they are awake and alert
- Keep the person **SAFE**
- Turn the person onto their **SIDE**

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**Cognitive Dysfunction in POTS**

**Brain Fog**

- Students experience brain fog, which is a common symptom of dysautonomia. Comprehension and memory storage/retrieval are impacted.
- Access to Teacher's notes to help memory retrieval.

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**Change In The Weather**

Students often notice an increase in symptoms early October (**October Slide**).

Low **barometric pressure systems**, which often occur before or around the time clouds and storms move in, may cause an increase in symptoms for students.

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### Extreme Fatigue

Many students experience chronic fatigue.

Students have issues with sleeping at night, waking up repeatedly and sweating.

A student with a chronic illness can get 12+ hours of sleep and still feel as their energy level is still at 10%.

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### At the beginning of the day and at the end of the day.

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### 2 SISTERS – Different Triggers

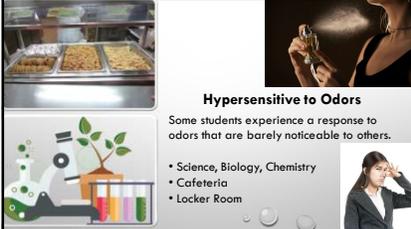
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| <ul style="list-style-type: none"> <li>GI Issues</li> <li>Heat Intolerance</li> <li>Low Blood Pressure</li> </ul>   | <ul style="list-style-type: none"> <li>Cold Intolerance</li> <li>Light Sensitivity</li> <li>Smell Sensitivity</li> <li>Noise Sensitivity</li> <li>High Blood Pressure</li> <li>Migraines</li> </ul> |
| <ul style="list-style-type: none"> <li>Chronic Fatigue</li> <li>Menstrual Cycle</li> <li>Constipation</li> <li>Musculoskeletal Pain</li> <li>Dehydration</li> <li>Stress</li> <li>October Slide</li> <li>Quick Movements</li> </ul> |   |

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### Some Students Have Major Hypersensitivities

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### Hypersensitive to Odors

Some students experience a response to odors that are barely noticeable to others.

- Science, Biology, Chemistry
- Cafeteria
- Locker Room

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### Solution to Hypersensitive Odors

A doctor can write a prescription to have Vicks in the nurse's station to block out odors.

The student can place a dab of Vicks under their nose, which will help block out odors.



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### Accommodations for Hypersensitivities

- Student should be allowed to sit, close to the teacher, or by the exit.
- Temperature sensitivity, avoiding placement next to the heater or air conditioner.
- Eating in a small area to avoid noise and odors sensitivity.

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### Light Sensitivities

Watching school videos, movies, TV shows or even the news with flashing lights can also trigger a syncope episode.

*Teachers please consider closing the blinds in the classroom and having the student wear their sunglasses to help when there is a lightning storm.*

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### Hypersensitivities to Lights:

- LED Lights
- Police Lights
- Ambulance Lights
- Fire Engine Lights
- Umbrella Flash Photography
- Lightening
- Strobe Lights
- Loud Noises



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**EXIT**

**Incase of an Emergency – Evacuation Plan**

It is imperative to educate school staff and administration of the emergency care plan

- Assign staff members to assist the student to evacuate.
- Practice fire drills and evacuations – (Please ensure that the student is not standing for long periods, especially in hot temperatures.)

**PLAN YOUR GREAT ESCAPE**

If an actual emergency occurs, then there needs to be an evacuation plan in place to help evacuate student from the building. *Strobe lights may cause a syncope episode.*

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**WHAT COULD GO WRONG?**

October 10, 2018

**A Nearly Three-Hour School Bus Ride Turns Into A Medical Emergency**

The latest incident reveals that the Houston Independent School District has yet to fix problems with its reorganized transportation system, three months after the start of school.

**TRANSCRIBE** | **ENCLOSURE** | **DOWNLOAD** | **SHARE**

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**BACK TO SCHOOL...  
...BACK TO BASICS**

**COMMUNICATION IS ABSOLUTELY ESSENTIAL!**

66

**SUBSTITUTE TEACHERS NEED TO BE NOTIFIED**

**SCHOOL ZONE**

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People with POTS are misdiagnosed for an average of 4.2 years prior to being diagnosed with POTS.

**DISAUTONOMIA AWARENESS**

[DysautonomiaInternational.org](http://DysautonomiaInternational.org)

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**Misdiagnosed?**

Most general pediatric doctors may not recognize the condition; many people go for years being misdiagnosed. Normally neurologist or cardiologist doctors will diagnose a student.

- 1<sup>st</sup> daughter, Ashley it took – 4 years after 15+ ER visits
- Due to awareness 2<sup>nd</sup> daughter, Alyssa was diagnosed in 2 months.

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**Tilt-Table Test**

A tilt-table test evaluates how the patient regulates blood pressure in response to simple stresses.

**Tilt Table Test: Testing for POTS**

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**How POTS is Diagnosed & Tested**

- Tilt Table Test
- 12-lead electrocardiogram (ECG)
- 24 hour blood pressure monitoring
- Blood tests – these may include full blood count, kidney and liver function, thyroid function, calcium, diabetes tests, lying and standing norepinephrine levels.
- Echocardiogram (cardiac echo)
- EEG (brain activity) & EMG (nerve function)
- MRI scan of brain

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**SCHOOL NURSES MAY HAVE TO HELP WITH 24 OR 48 HOUR ECG (HOLTER-MONITOR) DURING SCHOOL HOURS.**

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**Lifestyle Changes for POTS**

- Eat smaller meals
- Lower carbs/lean protein
- Examine your reaction to gluten
- Examine your reaction to dairy
- Examine your reaction to caffeine

73



Aqua therapy, occupational therapy, physical therapy is prescribed to help your student build up an exercise tolerance.

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**Having a POTS attack? Try this!**  
facebook.com/EileenDantolis

**Leg Crossing**

1. Stand with right leg crossed in front of your left leg
2. Square your legs together
3. Stand on a surface

Use a chair for support if needed.  
Helps move blood into your chest!

**Toe Raise**

1. Stand with feet back of your feet
2. Contract your calf muscles
3. Hold for 30 seconds
4. Relax and repeat 10 times

Helps pump blood back to your heart!

**Squat**

Avoid from a standing or sitting position to a squat.  
Squatting helps your heart closer to the floor and reduces the impact of gravity!

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**Durable Medical Equipment (DME) Assisted Devices**

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**Non-RX Treatments**

- LEARN WHAT WORKS FOR YOUR STUDENT TO REDUCE EPISODES
- STAYING HYDRATED
- INCREASE SALT (SODIUM)
- MEDICAL COMPRESSION STOCKINGS
- ABDOMINAL BINDERS
- RECLUMBENT EXERCISES
- GOOD SLEEP HABITS
- DIET LOW IN GLUTEN AND HIGH IN SODIUM
- COOLING VEST
- AVOID HEAT
- AVOID PROLONGED STANDING
- AVOID HOT SHOWER
- AVOID STAIRS - IF POSSIBLE
- AVOID CAFFEINE
- AVOID ALCOHOL
- EXERCISE AND AVOIDING STAYING IN BED ALL DAY LONG
- EDUCATE OTHERS ABOUT DYSAUTONMIA

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Sometimes our greatest gains are the things no one else sees. Those struggles beneath the surface



**The Iceberg Illusion**

**SUCCESS!** (WHAT PEOPLE SEE)

**WHAT PEOPLE DON'T SEE:** Persistence, Failure, Sacrifice, Disappointment, Good habits, Hard work, Dedication, Patience.

78

At the age of 15-years old, my daughter taught me to be a better parent. I had to learn to listen, what my child was trying to tell me.

**"Do you ever feel alone in a crowded room?"**



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**FRESHMAN YEAR**

**BIG SHOPPING ISSUE**

50 ways to have your wish come true!

**YOUR BIG-BA BROTHER**

**MAKUP LOOK TRENDS!**

**and more awesome content!**

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- The student needs the support of the ARD Committee and the School Nurse to develop the IEP.
- The student, parents, ARD committee and School Nurses are key decision makers in the ARD meeting. Working together will help to meet the student's needs.



**4 YEARS OF ARD MEETINGS WITH HIS**

**Just like that my child is a senior**

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School nurses have a critical roll in the IEP meetings, to help educate the ARD committee. The student has a medical need for support from the school health services and school nurse services.

With your support your student will feel like they are not alone, and that their voice matters.

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October is **dysautonomia** awareness month

learn more at [dysautonomiainternational.org](http://dysautonomiainternational.org)

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A doctor said it was all in her head, but it was 'the most common condition you've never heard of'

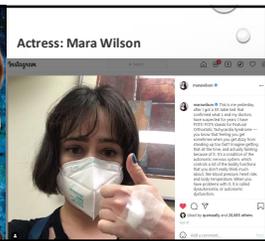


Philadelphia Eagles Super Bowl Champion Nick Foles's wife was also diagnosed with dysautonomia.

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Actress: Mara Wilson



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ARE YOU UP FOR THE CHALLENGE?

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Continuing Education:  
Region 6 Education Service Center In Huntsville, TX



June 2021

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YOUR SUPPORT COUNTS



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**Common Symptoms of Autonomic Dysfunction**

- Anxiety
- Blood Pooling In Lower Extremities (Hands & Feet (Purplish))
- Irregular Blood Pressure (Hypotension/Hypertension)
- Blurred Vision Or Tunnel Vision
- Brain Fog (Difficulty In Thinking)
- Chest Pain/ Tightness
- Chronic Fatigue
- Diarrhea/ Constipation
- Dilation Of Pupils
- Exercise Intolerance
- Fatigue
- Heat & Cold Intolerance
- Increase Heart Rate
- Insomnia / Sleep Disturbance
- Migraines
- Muscle Weakness/Pain
- Nausea/ Vomiting
- Sensitivity To Light (Photophobia)
- Sensitivity To Noise
- Sensitivity To Smell
- Sweating or Red Flushing
- Syncope (Fainting) or Near Fainting

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- Navigating on Easy IEP ( Individualized Education Plan) Special education under (IDEA).
- Creating IHP (Individual Health Plan).

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504 Accommodations

- General Education
- Accommodation provided to students due to:
- Frequent absences, brain fog, intermittent or partial homebound where student will be at home some days and some days at school to allow rest.

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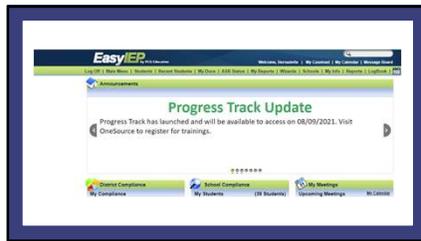
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- Health Office Anywhere: Dysautonomia / POTS condition has been added.
- Pathway

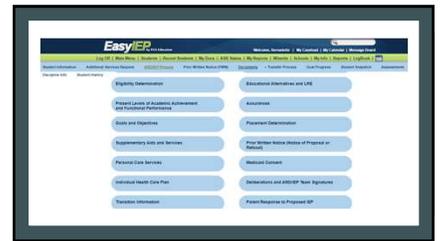
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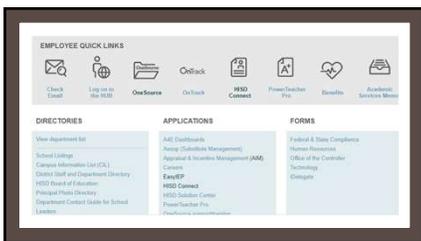
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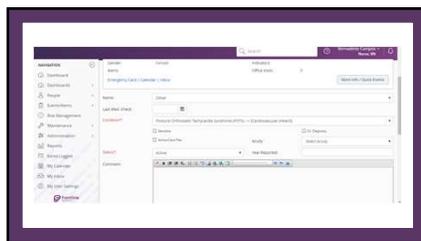
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