From Heart Rate to Digestion:

Autonomic Nervous System Function in People with Down Syndrome

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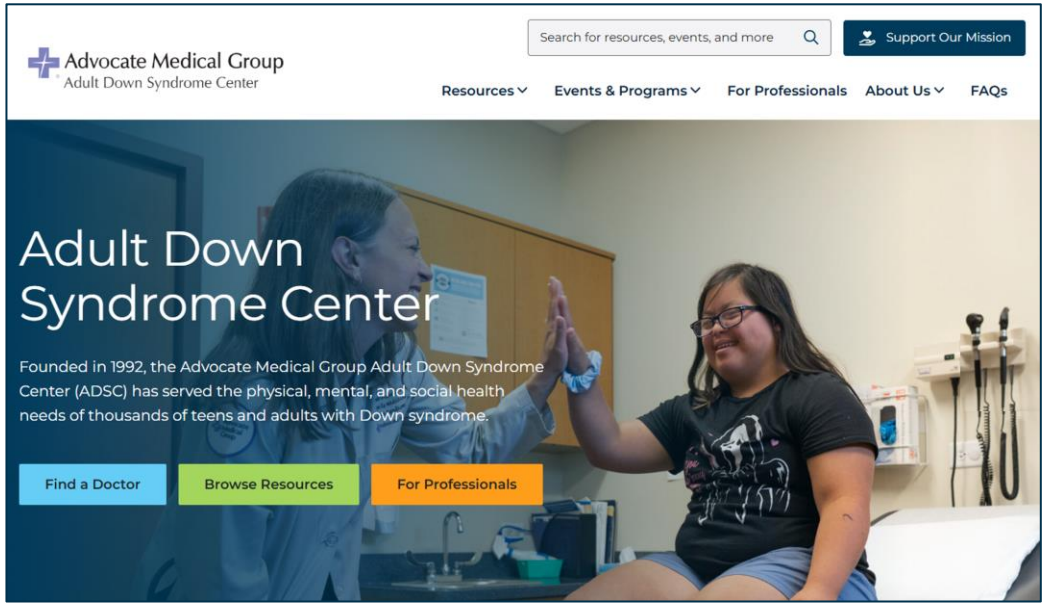

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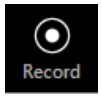
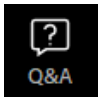
Reminders



- This webinar is being recorded.
  - The link to the recording and slides will be emailed to attendees within 1 week.



- Q&A
  - Please submit questions using the Q&A option.

Please note:

- This presentation is intended for families, caregivers, healthcare professionals, and service providers of individuals with Down syndrome.
- The information in this presentation is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.
- We are unable to provide diagnosis or treatment recommendations specific to an individual. We recommend that you bring specific questions about an individual with Down syndrome to their medical and/or therapy professionals.

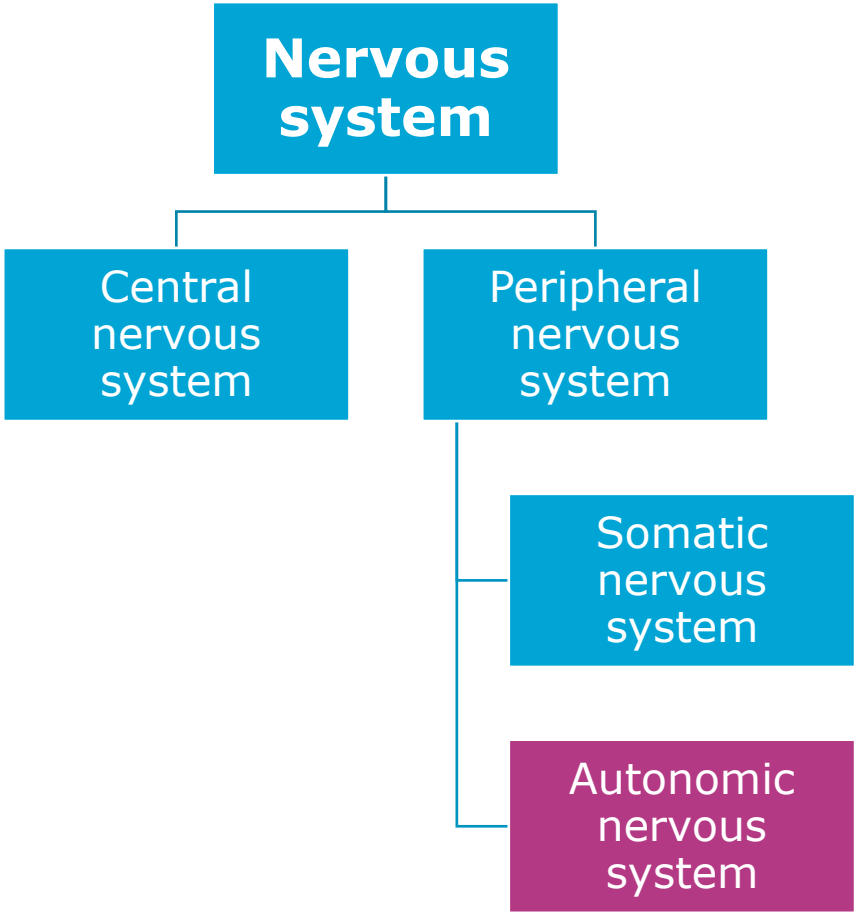
Brian Chicoine, MD

Autonomic Nervous System

Objectives

- Provide an overview
- Explain differences in people with Down syndrome
- Describe how it impacts various organ systems

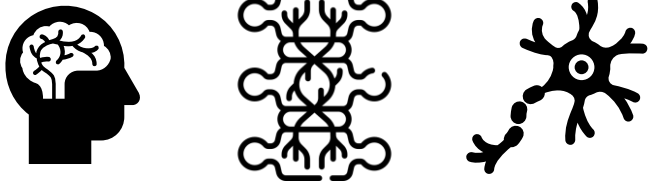
What is the autonomic nervous system?



The Nervous System

Body's "command center" that sends messages back and forth between the brain and other parts of the body.

- Brain
- Spinal cord
- Nerves



Autonomic nervous system (ANS)

- The part of the nervous system that functions automatically.
- Does not require our active thought processes.
- Controls a wide variety of functions:
  - Heart rate and blood pressure
  - Digestion
  - Urinary function
  - Temperature regulation
  - Many others

2 parts of the ANS

Sympathetic nervous system

- "Fight or flight"
- When activated:
  - Heart beats faster
  - Blood pressure rises
  - Sweating increases
  - Digestive function decreases

Parasympathetic nervous system

- "Rest and digest"
- When activated:
  - Heart beats slower
  - Blood pressure decreases
  - Sweating decreases
  - Digestive function increases

How is the autonomic nervous system different in people with Down syndrome?

Function of ANS

- In people with Down syndrome:
  - Reduced sympathetic (“fight or flight”)*
  - Increased parasympathetic (“rest and digest”)*
  - *Some studies report the opposite*

  - Other factors and body functions complicate the differences in organ function
    - Differences in collagen (connective tissue)
    - Low tone of smooth muscle
    - Sleep vs awake, activity vs rest
  - Differences in number of nerve cells in some organs

How do these autonomic nervous system differences affect various organ systems of people with Down syndrome?

Treatment

- There are no treatments specifically for differences in the autonomic nervous system.

- There are treatments for the effects caused by the differences in the autonomic nervous system.

Blood pressure

- Blood pressure (BP) = systolic/diastolic
  - Systolic = heart pumping
  - Diastolic = heart between beats
- Both tend to be lower
  - People without Down syndrome: 120/80
  - People with Down syndrome: 90-100/60-70 (or lower)
- Symptoms of low BP (hypotension)
  - Dizziness
  - Fainting
  - Fatigue
- Orthostatic hypotension

Blood pressure

- Additional considerations
  - Important to know a person's typical blood pressure
  - Anesthesia
  - Can be sensitive to developing symptoms with anything that further reduces blood pressure (e.g., infections, decrease in heart rate, dehydration)

- Management
  - Drink plenty of fluids
  - Consider salt intake
  - Get up slowly from lying or sitting
  - Compression garments
  - Medications (e.g., midodrine, droxidopa)
  - Is this related to the heart rate?

Heart rate/pulse

- Tends to be lower
  - People without Down syndrome: 60-100 bpm
  - People with Down syndrome: low 60s or even 50s
  - May not respond to situations when an elevated HR is expected and beneficial
    - Anesthesia
    - Exercise
- Symptoms of low heart rate (bradycardia)
  - Dizziness
  - Fainting
  - Sweating (less common in people with Down syndrome?)

Heart rate/pulse

- Additional considerations
  - More susceptible to factors that decrease heart rate such as pain, fear, and dehydration
  - Exercise – formula for determining target heart rate in exercise is different
    - 179 – (0.56 x age) = beats per minute
  - More rhythm disturbances
    - Congenital heart disease
    - Those without congenital heart disease

- Management
  - Treatments for low blood pressure may help
  - Consider pacemaker when appropriate

Fainting (vasovagal syncope)

- People with Down syndrome seem to be more at risk.
- Blood pressure
- Heart rate
- Increased sensitivity and response to stimuli that lower heart rate and blood pressure
  - Fear
  - Anxiety
  - Pain
- Psychogenic non-epileptic seizures (PNES, “fake seizures”) associated with changes in autonomic nervous system function
- Management
  - Same as management for blood pressure and heart rate/pulse

Postural orthostatic tachycardia syndrome

- Commonly called POTS
- Blood pressure remains the same
- Heart rate rises after standing
  - Sustained
  - Increases by $\geq$ 30 beats per minute
- Common symptoms
  - Dizziness, palpitations, lightheadedness, fatigue, “brain fog”, tremors, blurred vision, exercise intolerance (and others)
- Onset frequently precipitated by viral infection, surgery, prolonged bed rest, and others

Postural orthostatic tachycardia syndrome

- May be less common in Down syndrome

- Management
  - Exercise
  - Fluid and salt intake
  - Compression garments

- Variety of sub-types: autonomic neuropathy, increased norepinephrine (noradrenaline), low blood volume, and others

Acrocyanosis

- Discoloration of hands and feet
  - White or fair skin: usually bluish.
  - Darker skin: sometimes a color change, but it may not be blue; may become darker or may not be noticeable.
- Caused by constriction of small blood vessels
  - Painless
  - Normal response to cold temperatures
  - Can occur when not cold
- Greater sensitivity in people with Down syndrome
- Can contribute to dry skin
- Different than Raynaud's
  - Episodic
  - Vasospasm of arteries in hands
  - Paleness followed by cyanosis followed by redness (during rewarming)
  - Numbness, pins and needles, pain
- Management
  - Keep extremities warm
  - Skin care

Temperature regulation

- Temperature tends to be lower.
- Less fever (fever may not be a reliable indicator of infection)
- Some report less tolerance of the cold.
- Some report not feeling cold even when temperature is cold.

- Management
  - Hydration
  - Monitor for other signs of infection
  - Monitor for the need for weather-appropriate clothing
    - What is the contribution of sweating?

Sweating

- Some people with Down syndrome seem to sweat less.
  - Can contribute to overheating
- Management
  - Hydration
  - Monitor for the need for weather-appropriate clothing
  - Cool compresses
  - Limit exercise in very hot or humid conditions

Gastrointestinal tract

- Motility
  - Contraction/relaxation of muscles in the digestive tract that move food through the digestive tract
  - Typically, is slower in people with Down syndrome.
  - Slow motility can contribute to:
    - Constipation
    - Gastroesophageal reflux disease (GERD, heartburn)
    - Swallowing dysfunction

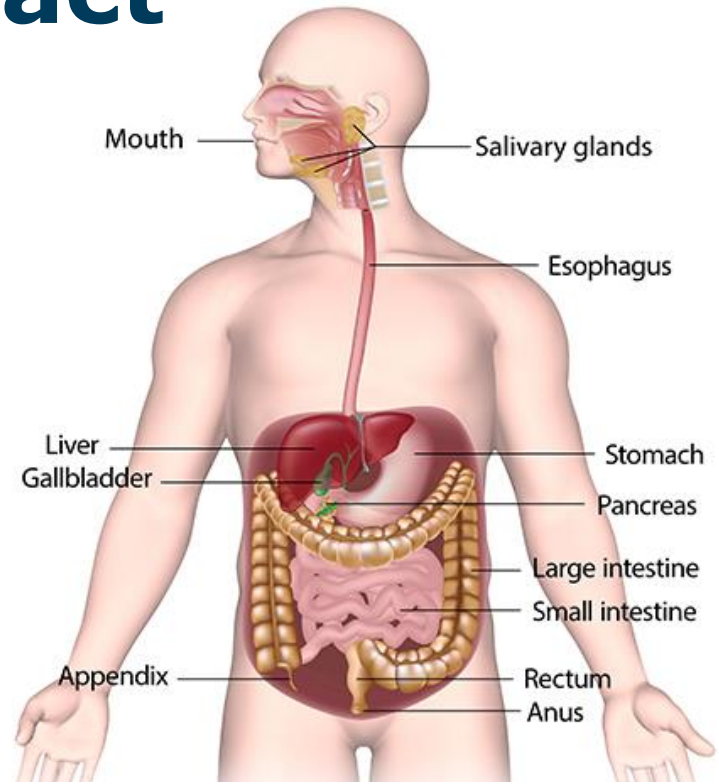


Image from the National Institute of Diabetes and Digestive and Kidney Diseases

Gastrointestinal tract

- Possible imbalance between parasympathetic and sympathetic
- Dyscoordination
- Decrease in nerve cells
- Differences in collagen (connective tissue)
- Low tone of smooth muscle

- Management
  - See recording of 2-part webinar series on Gastrointestinal Health of People with Down Syndrome.

Metabolism

- Autonomic nervous system affects:
  - Glucose metabolism
  - Lipid metabolism
  - Energy expenditure
  - Insulin secretion
  - Nutrient feedback
  - And others

- Down syndrome
  - Autonomic nervous system and metabolic differences are found in people with Down syndrome.
  - Link between the two needs more study.

Urinary retention

- Inability to empty one's urinary bladder
- Complications or symptoms
  - Difficulty starting urinary stream
  - Bladder infections
  - Can contribute to kidney damage
  - Urinary incontinence
- Causes
  - Dyscoordination between bladder contraction and sphincter relaxation
  - Connective tissue (weakness or decreased tone of the bladder muscle)
  - Can be worsened by holding urine for long periods of time
- Management – dependent on cause
  - Timed toileting
    - Using the bathroom every 2-3 hours
    - Timers
  - Medications
  - Catheters
  - Surgery

Asthma

- Narrowing of the airways that causes wheezing
- Seems to be *less* common rather than more common
  - Lower frequency of allergies may contribute

Autoimmunity

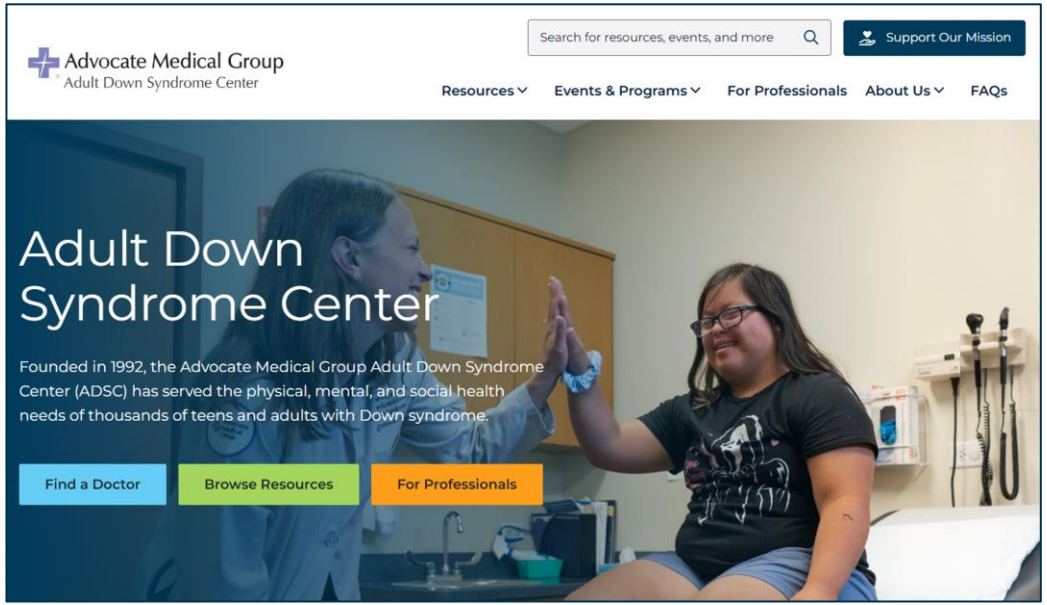
- Autoimmune disease is more common in people with Down syndrome
- The immune system can attack the autonomic nervous system
  - Achalasia (esophagus)
  - Cardiac autonomic dysfunction
    - Systemic lupus
    - Sjogren’s syndrome
    - Rheumatoid arthritis
- Management
  - Treatment of resulting symptoms
  - Possible future prevention and/or treatment?

Wrap-up

- Autonomic nervous system function is different in people with Down syndrome.
- There is complexity and variability in the autonomic nervous system in Down syndrome.
- Awareness
- Be observant
- Prevention
- The function and the effects may change over time.
  - Function changes with aging
  - Early aging in people with Down syndrome
  - Alzheimer’s disease further impairs autonomic nervous system function
- Change in function deserves evaluation and treatment

Resources & References

Resource Library



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ADSC resources

- **Articles**
  - Acrocyanosis
  - Anesthesia
  - Compression Socks
  - Connective Tissue
  - Constipation
  - Dysphagia (Swallowing Problems)
  - Syncope (Fainting)
  - Function of the Autonomic Nervous System
  - GERD
  - Heart Rates and Exercise
  - Hypertension and Hypotension (High and Low Blood Pressure)
  - Irritable Bowel Syndrome
  - Temperature Regulation
  - Urinary Incontinence
  - Urinary Retention
  - Venous Disease
  - Warning Signs a Person with Down Syndrome is Getting Overheated
  - Weight Management
- **Webinar**
  - Gastrointestinal Health of People with Down Syndrome

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Interdisciplinary group of healthcare professionals who care for people with Down syndrome

- Membership
- Project ECHO
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References

- Boer PH. Accuracy of the prediction equation for the determination of maximum heart rate in adults with Down syndrome. *J Intellect Disabil Res*. 2017;61(1):83-88. doi:10.1111/jir.12345
- Ciciora SL, Manickam K, Saps M. Disorders of gut-brain interaction in a national cohort of children with Down syndrome. *J Neurogastroenterol Motil*. 2023;29(1):94-101. doi:10.5056/jnm22055
- Cilhoroz BT, Receno CN, Heffernan KS, Deruisseau LR. Cardiovascular physiology and pathophysiology in Down syndrome. *Physiol Res*. 2022;71(1):1-16. doi:10.33549/physiolres.934791
- Dębiec-Bąk, A., Wójtowicz, D., Pawik, Ł. et al. Analysis of body surface temperatures in people with Down syndrome after general rehabilitation exercise. *J Therm Anal Calorim*. 2019;135, 2399–2410. doi:10.1007/s10973-018-7345-1
- Dey A, Bhowmik K, Chatterjee A, Chakrabarty PB, Sinha S, Mukhopadhyay K. Down syndrome related muscle hypotonia: Association with COL6A3 functional SNP rs2270669. *Front Genet*. 2013;4:57. doi:10.3389/fgene.2013.00057
- Foley C, Killeen OG. Musculoskeletal anomalies in children with Down syndrome: An observational study. *Arch Dis Child*. 2019;104(5):482-487. doi:10.1136/archdischild-2018-315751

References

- Graham MF, Drucker DE, Diegelmann RF, Elson CO. Collagen synthesis by human intestinal smooth muscle cells in culture. *Gastroenterology*. 1987;92(2):400-405. doi:10.1016/0016-5085(87)90134-x
- Hilgenkamp TIM, Wee SO, Schroeder EC, Baynard T, Fernhall B. Peripheral blood flow regulation in response to sympathetic stimulation in individuals with Down syndrome. *Artery Res*. 2018;24:16-21. doi:10.1016/j.artres.2018.10.001
- Imamura M, Mukaino A, Takamatsu K, et al. Ganglionic acetylcholine receptor antibodies and autonomic dysfunction in autoimmune rheumatic diseases. *Int J Mol Sci*. 2020;21(4):1332. doi:10.3390/ijms21041332
- Schill EM, Wright CM, Jamil A, LaCombe JM, Roper RJ, Heuckeroth RO. Down syndrome mouse models have an abnormal enteric nervous system. *JCI Insight*. 2019;5(11):e124510. doi:10.1172/jci.insight.124510
- Sinton JW, Cooper DS, Wiley S. Down syndrome and the autonomic nervous system, an educational review for the anesthesiologist. *Paediatr Anaesth*. 2022;32(5):609-616. doi:10.1111/pan.14416

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