



## Cerebral Palsy

Victory Junction Medical Staff and Volunteer Training



## Objectives – What's the target?

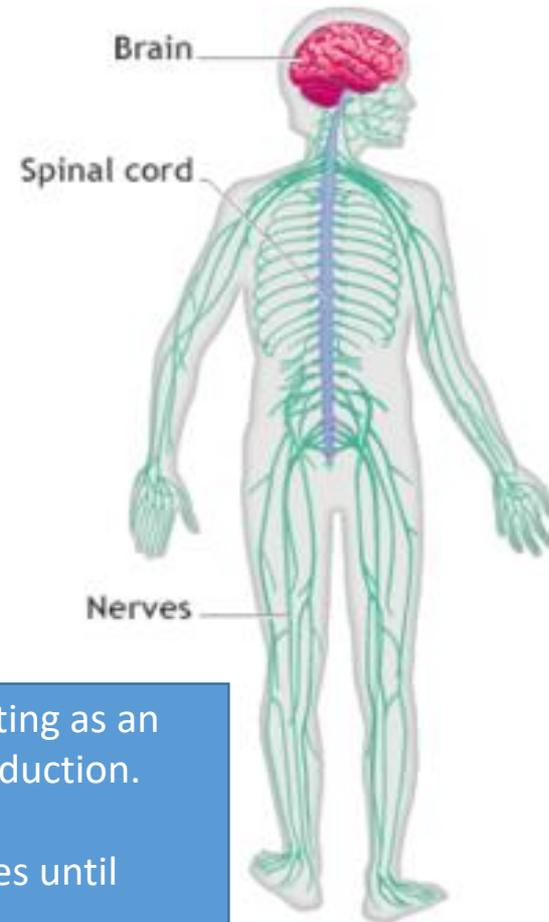
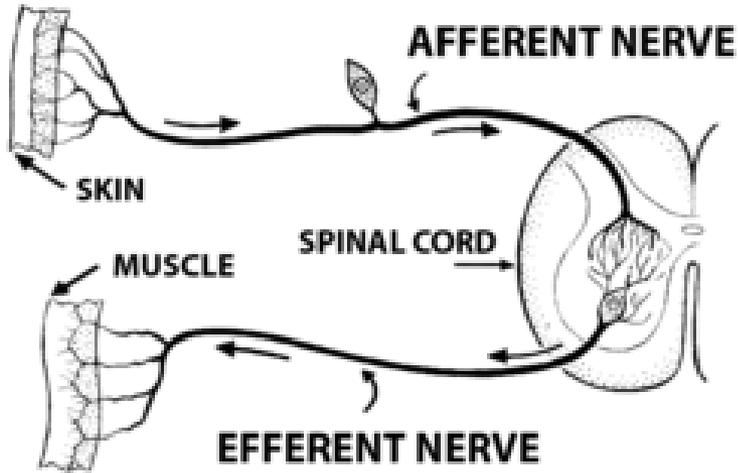
- Review basic normal physiology of the neurological system
- Cerebral Palsy
  - Review basic pathophysiology
  - Discuss common complications and emergencies
  - Discuss treatment of cerebral palsy
  - Discuss care of campers with cerebral palsy at Victory Junction



The target is camper safety! Better understanding of the disorders our campers are living with means better care!

# Central Nervous System

The central nervous system includes the brain, spinal cord, and nerves.



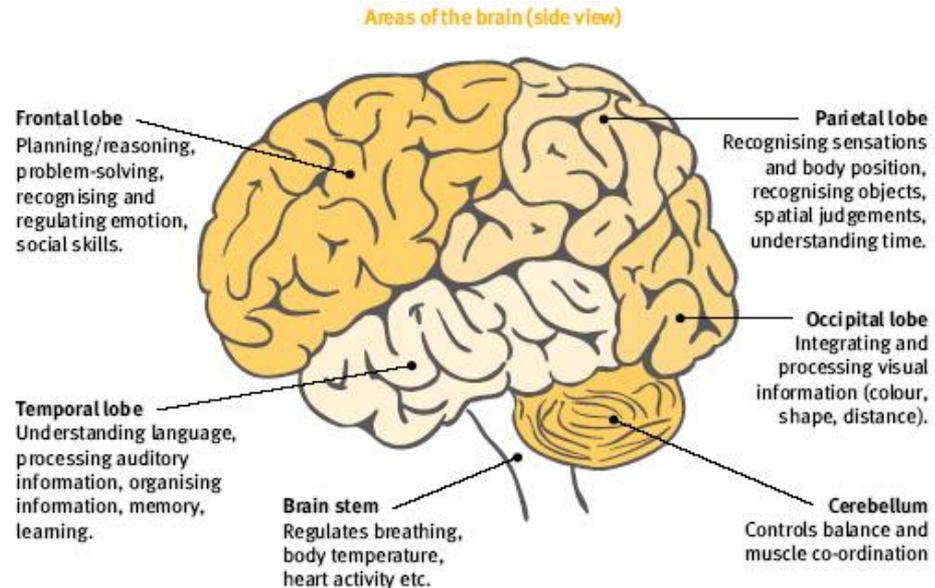
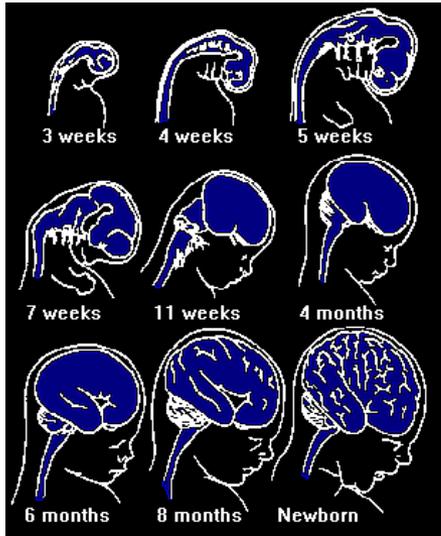
Nerves communicate sensory information to the CNS and motor information from the CNS to muscles.

Myelin is a fatty substance that surrounds some neurons, acting as an electrically insulating layer, and increasing the speed of conduction.

Myelination begins during fetal development and continues until adolescence.



# Central Nervous System Development



The cerebellum is affected in those with cerebral palsy.

Brain development is a process that occurs in stages over time, with 3 key factors.

- **Genetics** – Genes create templates for proteins essential to the development process.
- **Environment** – provides essential input that influences the developing system
- **Time** – Each step of the developmental process depends on the availability of the appropriate elements at the appropriate time. A flaw in the developmental process will affect the following stages.

# What is Cerebral Palsy?

Cerebral palsy (CP) describes a group of neurological disorders that affect muscle coordination and movement. CP is caused by a malformation or damage to the brain during development. CP is described as either congenital or acquired, depending on the timing of the malformation or brain damage.

Congenital CP (before or during birth)	Acquired CP (after 28 days of life)
85-90% of cases (<10% from lack of oxygen during birth)	Much smaller percentage, 10-15% of cases
Causes: Unknown specific cause	Causes: infection (encephalitis, meningitis), injury (abuse, MVA), obstruction of blood flow to brain (i.e. stroke, hemorrhage, or vascular problem)
Risk factors: low birth weight, maternal infection during pregnancy, multiple births, assisted reproductive technology pregnancy, jaundice, problems during the delivery	Risk factors: infancy, low birth weight

# Cerebral Palsy

- CP is the most common motor disability in children
- About 1 in 323 children are diagnosed with CP
- CP is more common in boys than in girls.
- In 2008 CDC data, CP was more common in black children than white, with similar occurrence in Hispanic and white children
- Over half of the children with CP had a co-occurring illness
  - 41% had co-occurring epilepsy
  - 6.9% had co-occurring autism spectrum disorder
- A 2006 study of children with CP in Atlanta reported that over 40% also had an intellectual disability, and nearly 1 in 4 children with CP also had both epilepsy and an intellectual disability



# Types of Cerebral Palsy

People with dyskinetic (includes athetoid) CP may have difficulties swallowing, sucking, talking, and walking. Their muscle tone may vary between too tight and too loose frequently.

Spastic CP affects about 80% of all people with CP.

Tight, contracted muscles may affect one side more than the other (hemiplegia), lower body more than upper (diplegia), or all four limbs (quadriplegia).

## TYPES OF CEREBRAL PALSY

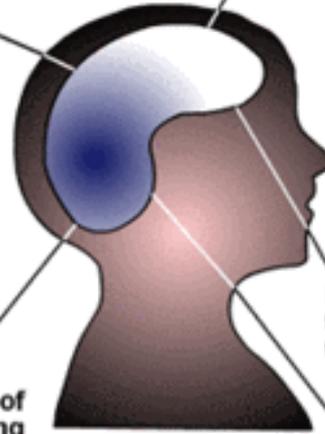
**SPASTIC-** tense, contracted muscles (most common type of CP).

**ATHETOID-** constant, uncontrolled motion of limbs, head, and eyes.

**ATAXIC-** poor sense of balance, often causing falls and stumbles

**RIGIDITY-** tight muscles that resist effort to make them move.

**TREMOR-** uncontrollable shaking, interfering with coordination.



A person can have more than one type of CP. The most common mixed CP is spastic-dyskinetic.

# Cerebral Palsy Diagnosis and Treatment

The process of diagnosing cerebral palsy in a child is lengthy.

Evaluation typically occurs as developmental screenings and tests.

Parents may become concerned if their child feels too tight or too floppy as an infant, does not move all limbs with similar strength and coordination, or meet motor development milestones like rolling over, sitting unassisted, and crawling.

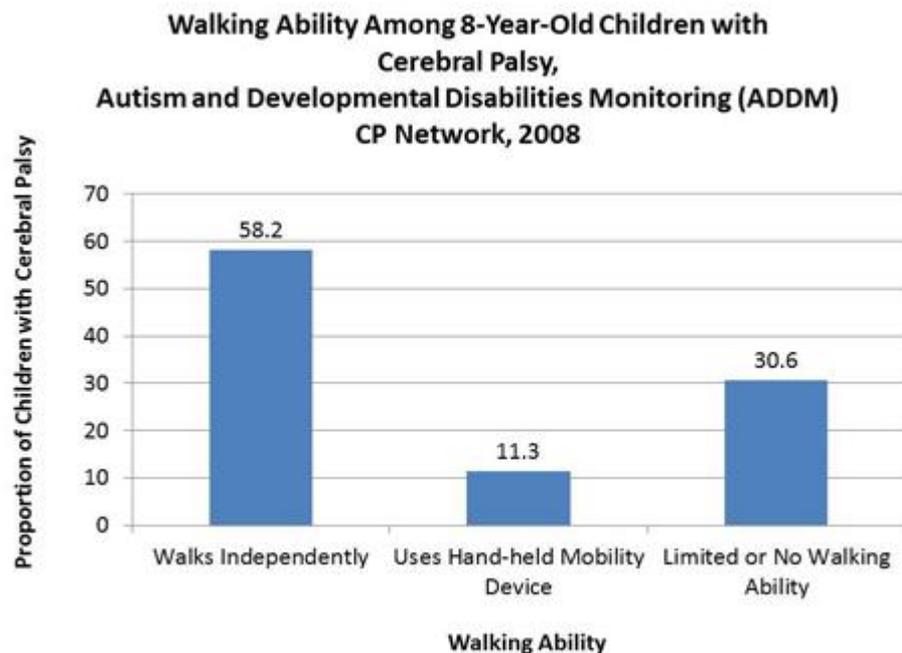


There is no cure for CP. It is a non-progressive disorder, meaning it does not worsen over time. Treatment plans may involve medicine, surgery, and physical/occupation/speech therapies.



# Cerebral Palsy Complications

The primary complication of cerebral palsy is limited mobility.



In this group of children with CP, over half (58.2%) could walk independently. Others (11.3%) used a hand-held device, such as crutches or a walker, and about one-third (30.6%) had very limited to no walking ability and use a wheelchair.

Centers for Disease Control. (2015). Data and statistics for cerebral palsy. Retrieved from <http://www.cdc.gov/ncbddd/cp/data.html>



# Cerebral Palsy Associated Complications

Intellectual disability and autism-spectrum disorder are conditions that are often associated in children with cerebral palsy.



There is an incredibly wide range of functioning levels and abilities among this group. NEVER assume a child's ability.

The Victory Junction Camper Care Form will list any co-morbidities.

Counselors are trained to communicate with these campers and manage behaviors, along with the full time program staff.

As a medical volunteer, you can help by supporting and understanding.



# Cerebral Palsy Associated Complications

Other co-morbidities:

1. OCD (obsessive compulsive disorder)
2. ODD (oppositional defiant disorder)
3. Behavior problems
4. Anxiety
5. Depression
6. Speech impairments
7. Dysphagia

Some campers may require:

- Feeding tubes (G-tubes and J-tubes)
- Pureed foods
  - Or assistance with feeding
- Communication devices
  - iPads
  - Eye gaze devices

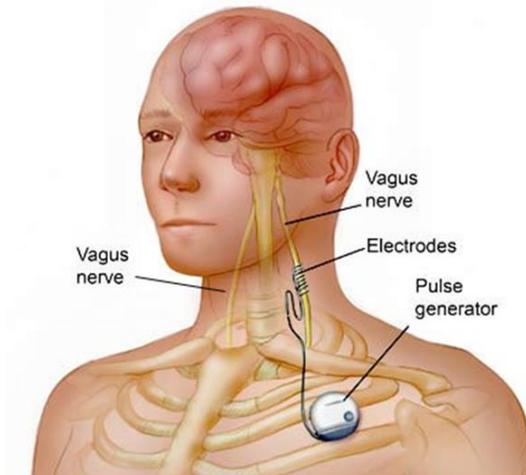
For campers with behavior problems while at camp, please utilize the Program Team!

- Austin Wiser, Will Wright, Jacob Byrd, and Renee Gimber are here to help you!
- Austin Wiser is a Child Life Specialist, specializing in behavior at camp. Don't be afraid to reach out!

# Camp Life

- Campers may carry emergency anti-seizure medication with them
- Some campers will have multiple magnets for a vagal nerve stimulator (this is used to prevent or help stop a seizure once it has started).
- The magnet will need to be with the designated counselor for that camper at all times!!!
- Talk to the parents about the characteristics of their child's seizure
- Some campers may have special, very strict, diets used to control their seizures

Report any suspected seizure activity to your Unit Nurse or the Body Shop!



# Seizure First Aid

STAY CALM!!!!

Don't forget to call for help! (x2000)

Crowd control

- **In the pool, keep camper's head above water**
- **On a boat, lay the camper down and bring the boat to shore**



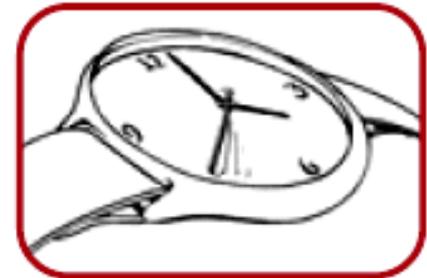
1. Cushion head, remove glasses.



2. Loosen tight clothing.



3. Turn on side and keep airway clear.



4. Note the time a seizure starts and the length of time it lasts.



5. Don't put anything in mouth.



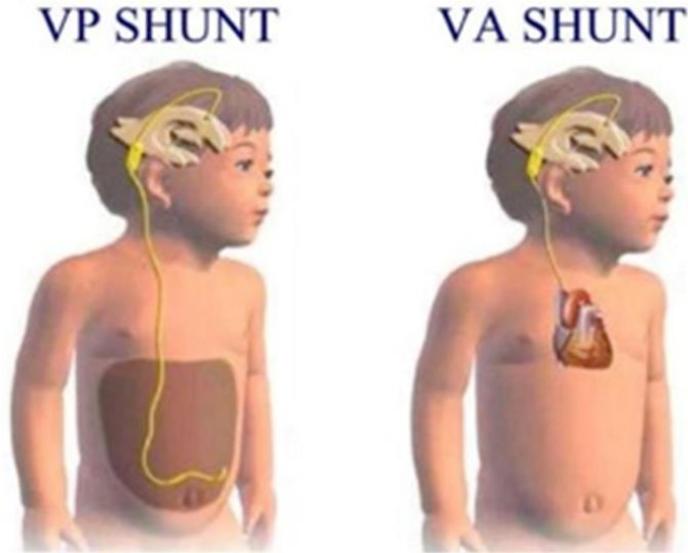
6. Don't hold down.

7. As seizure ends...offer help.

# Cerebral Palsy Associated Complications and Emergencies

Hydrocephalus is a birth defect that impacts the brain, and some children with CP, who also have hydrocephalus, have had a shunt placed.

A shunt allows this extra fluid to drain from the ventricles into the peritoneal space (VP) or atrium (VA), reducing pressure on the brain.



In a camper with a shunt, we are concerned about:

- Change in level of consciousness (extreme agitation, behavior change, extreme/unusual fatigue)
- Headaches
- Vomiting

\*Information about a camper's shunt is found on the Camper Care Form in CampSite.\*

# Cerebral Palsy Treatment

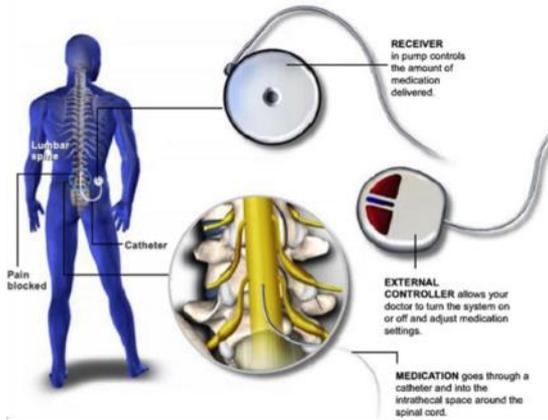
Treatments for cerebral palsy focus on managing the symptoms to improve muscle strength, coordination, and functioning. Anticholinergic and antispasmodic medications are common in CP management.

	Anticholinergic medications	Antispasmodic (“muscle relaxer”) medications
Mechanism of Action	<ul style="list-style-type: none"><li>• Block acetylcholine, the neurotransmitter that triggers muscle movement</li><li>• Used to treat uncontrolled movements, tight muscles, spastic GI tract, and excessive saliva or bronchial secretions</li></ul>	<ul style="list-style-type: none"><li>• Baclofen – Blocks signal between spinal cord and muscles</li><li>• Diazepam – relaxes/slows signals in the brain and in the muscles</li><li>• Dantrolene – interferes with muscle contraction</li><li>• Used to treat generalized spasticity</li></ul>
Examples of medication names	<ul style="list-style-type: none"><li>• Benztropine mesylate</li><li>• Carbidopa-levodopa (Sinemet)</li><li>• Glycopyrrolate (Robinul)</li><li>• Procyclidine hydrochloride (Kemadrin)</li><li>• Trihexyphenidyl hydrochloride</li></ul>	<ul style="list-style-type: none"><li>• Baclofen (Lioresal)</li><li>• Diazepam (Valium)</li><li>• Dantrolene (Dantrium)</li></ul>
Common side effects	<ul style="list-style-type: none"><li>• Dry mouth</li><li>• Blurry vision</li><li>• Constipation</li></ul>	<ul style="list-style-type: none"><li>• Drowsiness</li><li>• Weakness</li><li>• Nausea</li><li>• Skin rash</li></ul>
Camper considerations	<ul style="list-style-type: none"><li>• Keep campers hydrated!</li><li>• Diphenhydramine (and other antihistamines) may be Forbidden OTCs</li></ul>	<ul style="list-style-type: none"><li>• Always check dosages, verify most current dose and timing at medical check-in</li></ul>



# Cerebral Palsy Treatment

Baclofen can also be administered intrathecally via implanted pump. Administering the medication continuously and directly to the spinal fluid may have an improved effect on muscle tone and control with smaller doses of baclofen, for some people with CP.



The pump is surgically placed beneath the skin, usually in the lower abdomen. A catheter delivers medication directly into the fluid surrounding the spinal cord. The pump is refilled with medication every 2-3 months.

In rare cases, the pump can malfunction or have problems. If you suspect a camper has problems with their baclofen pump, notify the provider on call and Director of Medical Operations immediately.

Symptoms of abrupt withdrawal: itching, rebound spasticity, tachycardia  
Symptoms of overdose: decreased level of consciousness, respiratory failure

# Cerebral Palsy Treatments

Campers with CP and co-occurring epilepsy will take medications to prevent seizures.

Anticonvulsants reduce or depress excessive stimulation in the brain, although different medications are used to treat different types of seizures.

## Common anticonvulsants:

- Levetiracetam (Keppra)
- Lamotrigine (Lamictal)
- Oxcarbazepine (Trileptal)
- Ethosuximide (Zaronin)
- Valproic acid (Depakote)

## Common side effects (may vary):

- Fatigue
- Dizziness
- Headaches
- Constipation
- Nausea

- Campers may take multiple anticonvulsants, or switch from one medication to another at the advice of their provider.
- **Verify that the medications, timing, and dosages to be given during camp are the most recent prescription for the camper.**
- Add additional pertinent information about a camper's seizures to the unit nurse notes in CampSite.



# Cerebral Palsy Treatment

Treatment plans often include physical, occupational, and speech therapy.



Orthopedic surgery is also used to improve function, mobility, or decrease pain. Some common surgery goals include:

- Tendon release, lengthen tendons or muscles
- Correcting a curvature in the spine
- Correct uneven leg length
- Correct hip dislocation
- Release tight muscles/contractures
- Stabilize joints

Cerebral Palsy is treated with a multidisciplinary approach, and each individual is different.



# Cerebral Palsy and Mobility Aids



Campers with CP may use a variety of mobility aids, including:

- Wheelchair (power or manual)
- Ankle-foot orthotics (AFOs)
- Crutches
- Walker
- Gait trainer
- Braces



# Cerebral Palsy and Mobility at Victory Junction

Cabin counselors and volunteers are responsible for helping campers as needed with their ADL's, including use of AFOs and braces.

As a medical volunteer, you can help by:

- Ensuring the cabin counselors and volunteers are comfortable with proper use of these devices
- Inform the cabin counselors and volunteers about any additional instructions (i.e. a camper that must wear AFOs when ambulating, but not if using a wheelchair, or a camper that wears wrist braces on/off every 2 hours)
- Ensure the camper's skin integrity is checked with daily care, and that counselors notify the nurse if they notice any breakdown



# Mobility at Victory Junction

Campers may use a wheelchair for mobility.

Wheelchair safety at camp:

- Every should wear closed-toe shoes.
- Brakes on!
- Don't encourage racing.



A camper's wheelchair is an extension of him/herself.

Wheelchair etiquette at camp:

- Allow independence, do not push a camper's chair without asking.
  - Avoid leaning on a camper's wheelchair.
    - Get on the camper's level.

As a medical volunteer, you should help reinforce this etiquette with counselors and volunteers.

# Cerebral Palsy at Victory Junction

What we want you to know at camp:

- Some campers will have trouble eating
- Some campers may have difficulty communicating
- Some campers may need help with toileting and changing
- Do not assume these campers have intellectual disabilities.



# Cerebral Palsy at Victory Junction

How can you help the campers?

- Check their skin frequently for pressure sores or breakdown
  - Each camper will be checked every night for pressure sores
    - Check all extremities and trunk
- Report any new or unusual seizures to the medical team
  - Some campers may have several seizures a day at their baseline and that's ok!
- Listen to your campers and note any subtle changes!
- A camper said it best, "Don't dis my ability!"



# Things to Remember...

- Every child is unique. Do your best to get to know your campers and listen to them!
- We do our best to stick to campers' home routines. Medications and treatments should be done the way they are done at home as much as possible.
- As a volunteer, you are not expected to be an expert in everything. We welcome your knowledge and experience and aim to work as a team!
- The unit nurses, full time staff, and specialist providers are excellent resources and here to help. Always ask if you are unsure or concerned about a medication, treatment, or camper's condition.



# Questions



Bring your questions with you, and get ready for a great week!!



Thank  
you!

