

Kids Get MS Too!



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Objectives

- Define Multiple Sclerosis (MS)
- Discuss the cause and effect of MS
- Discuss the diagnosis and treatment of pediatric onset MS
- Discuss the impact of diagnosing pediatric MS
- Discuss specialized treatment that is necessary with a Pediatric MS diagnosis



Defining MS And Its Causes and Effects

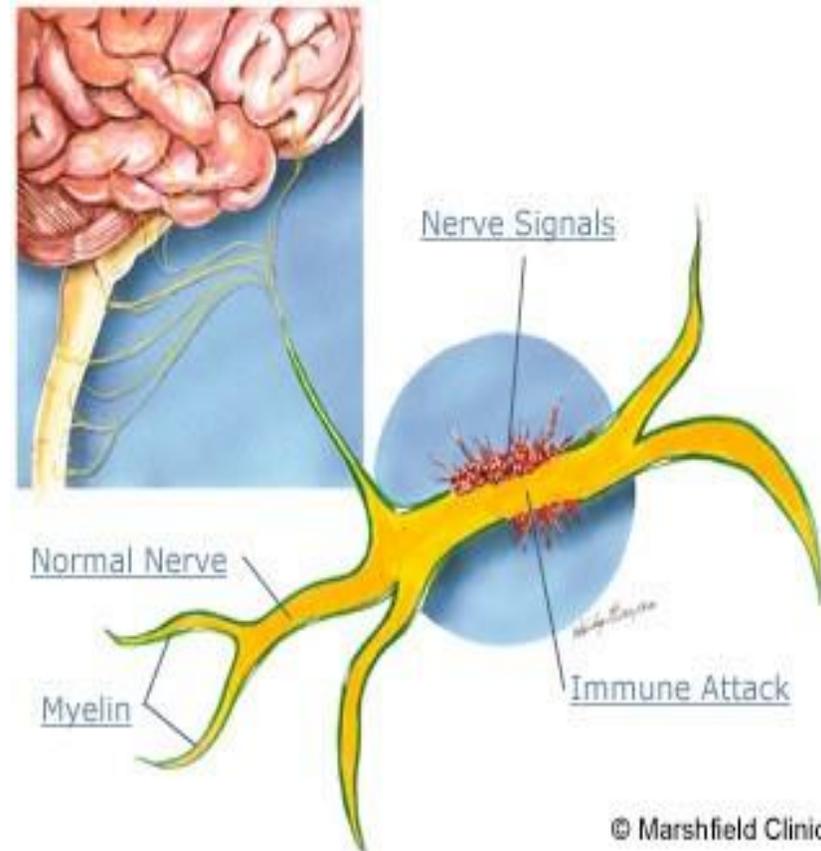


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What is Multiple Sclerosis ?

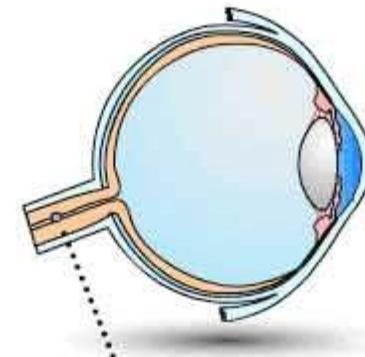
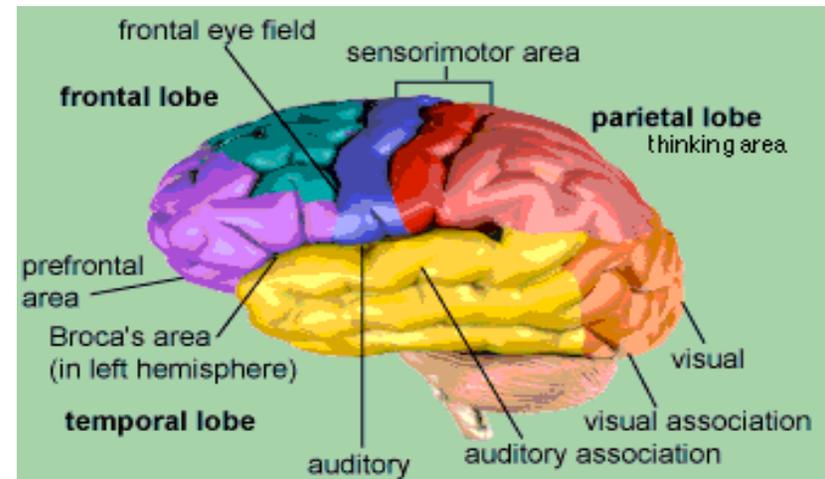
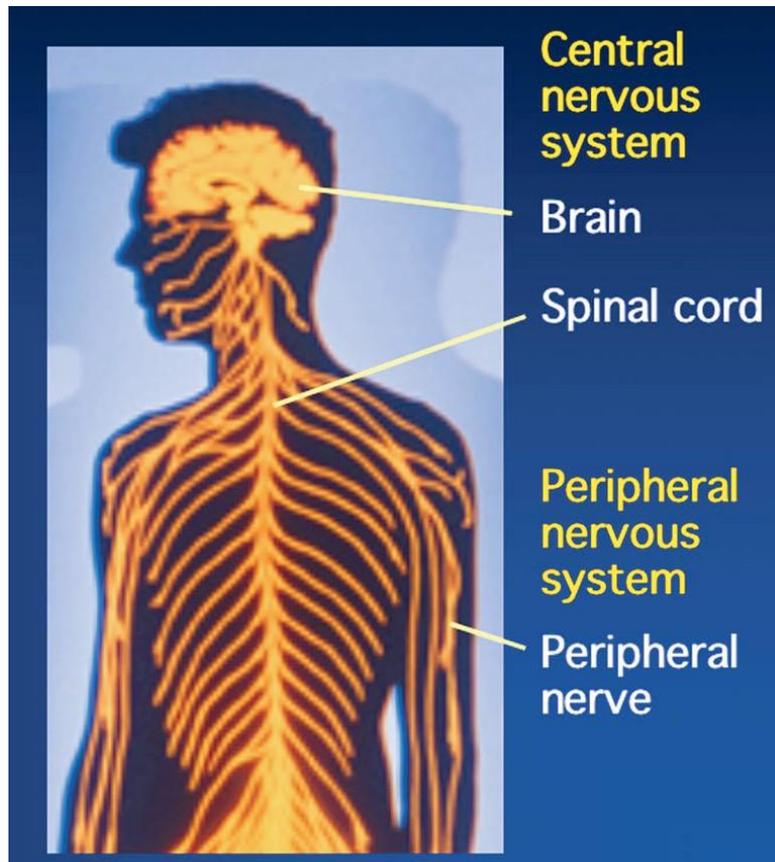
- An autoimmune disease that affects the central nervous system (CNS)
- The immune system mistakenly attacks the body's myelin and cause the nerves to be damaged causing scarring
- The scarring begins to slow and interrupt the transmission of nerve impulses, resulting in the symptoms of MS





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MS Affects the Brain, Spinal Cord and Optic Nerves



What Causes MS?

- Genetic predisposition to react to some infectious agents in the environment such as a virus or bacteria
- Different viruses and bacteria have been studied for their possible role in MS
- Environmental components have been considered



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Who Gets MS?

- There are approximately 450, 000 people with MS in the US and Canada (1 in 1,000) people have the disease at any given time
- Diagnosis is typically between the ages 20 and 50
- Studies indicate that 2.7% - 5% of people with MS are diagnosed before the age of 16



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MS Prevalence

- MS is more common in women than in men
- MS is more frequent in Caucasians than in Hispanics or African Americans and is rare among Asians and other groups
- More common in temperate areas of the world, away from the equator
- Risk is greatest in families that have several family members with a diagnosis

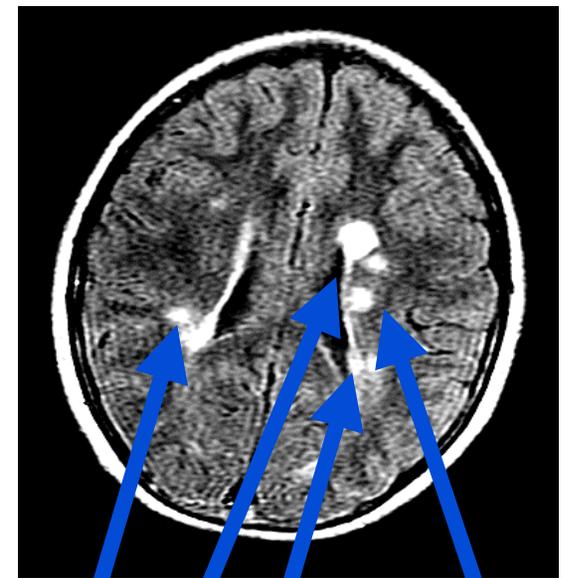
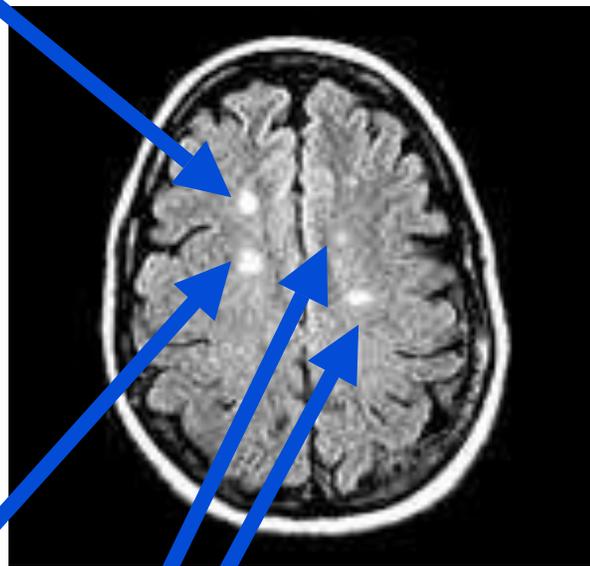
What Happens When a Person Gets MS?

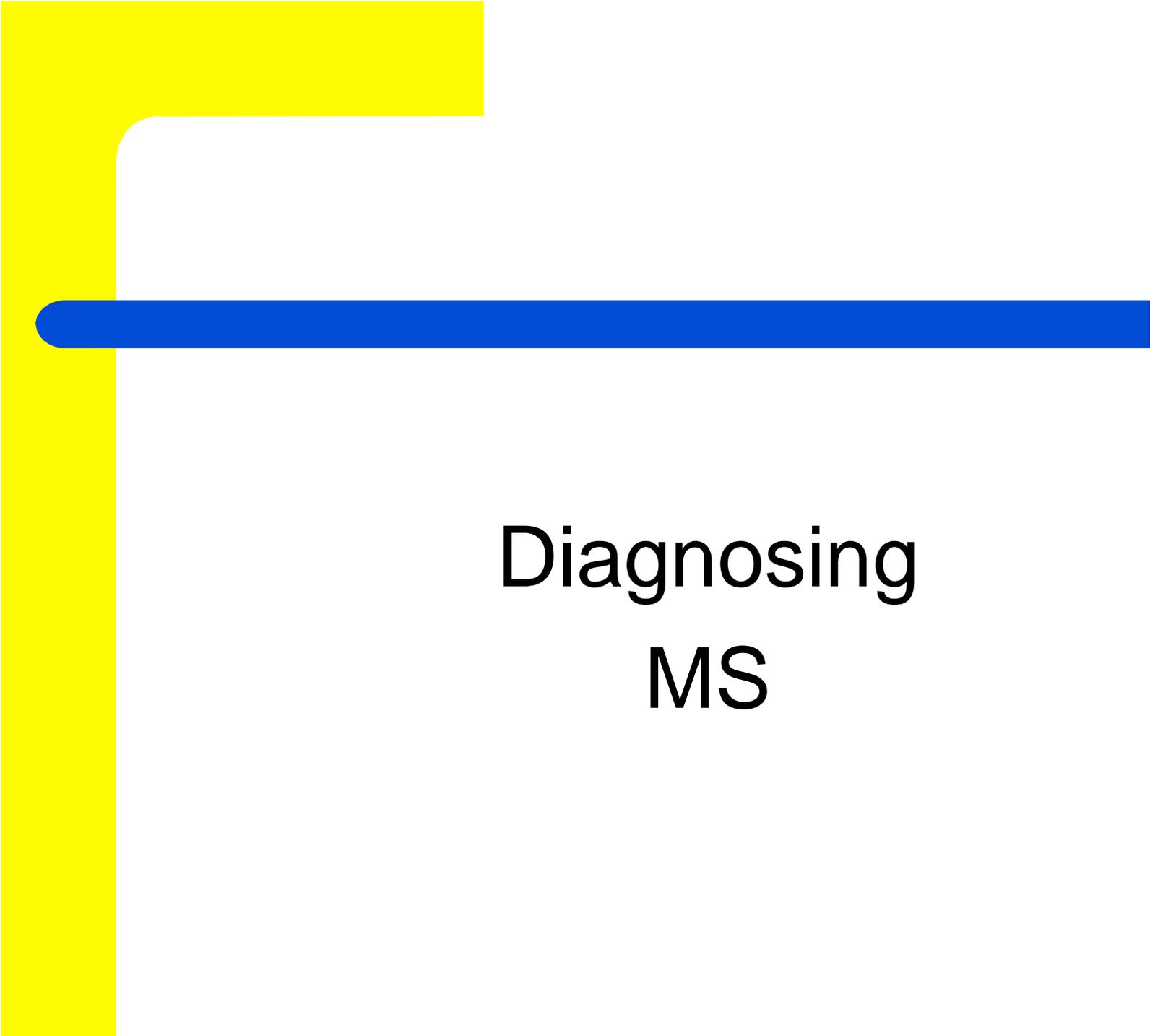
- Misguided immune cells enter the CNS
- Inflammation in the brain, spinal cord and/or optic nerves
- Inflammation causes damage to the coating or myelin around the nerve cells, causing scarring or demyelination and the formation of lesions that prevent nerve transmission



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MS Brain and Spinal Lesions



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Diagnosing MS

Diagnostic Tools Used

- Medical History
- Neurological exam
- Serial Magnetic Resonance Imaging (MRI)
- Laboratory Test
 - Serum
- Spinal Tap
 - Spinal Fluid
- Evoked Potentials



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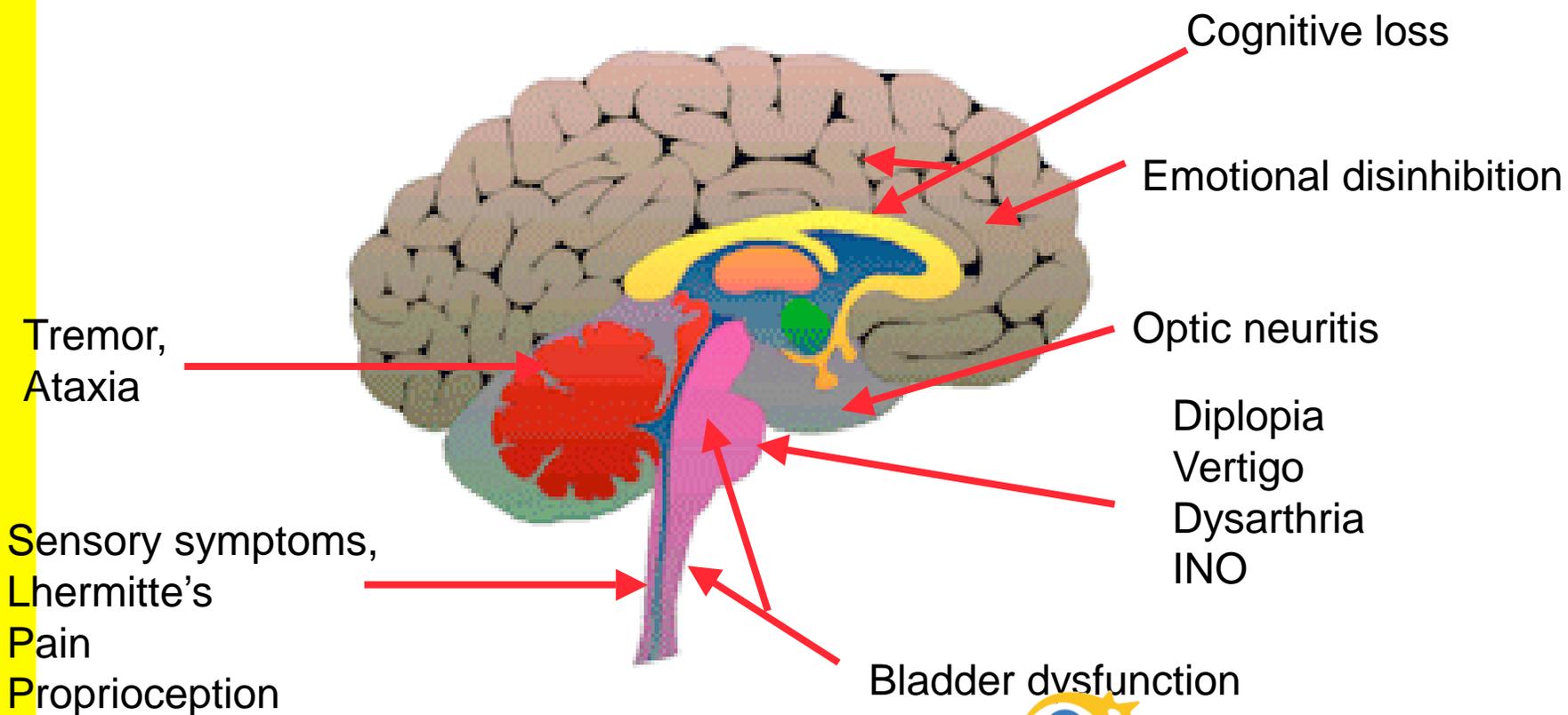
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Possible Initial and Ongoing MS Symptoms

- Tingling, numbness or pain in one part of the body
- Problems with balance and/or coordination
- Muscle weakness in one part of the body
- Spasticity (Stiffness)
- Sexual changes
- Changes in vision
- Fatigue
- Slurred speech or stuttering
- Changes in bladder or bowel function
- Cognitive changes
- Depression or other emotional changes



Sources of Symptoms



Symptoms vary widely in incidence and severity



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Factors That Can Affect MS Symptoms

- ❑ Quality of coping skills
 - Anxiety and depression can heighten reactions to symptoms
- ❑ Temperature
 - External temperature, strenuous physical activity, fever
- ❑ Infections



5 Types of MS

- Benign MS
- Relapsing Remitting MS
- Primary Progressive MS
- Secondary Progressive MS
- * Progressive Relapsing MS



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Long term outcome of MS

“Benign” MS

Relapsing-remitting MS

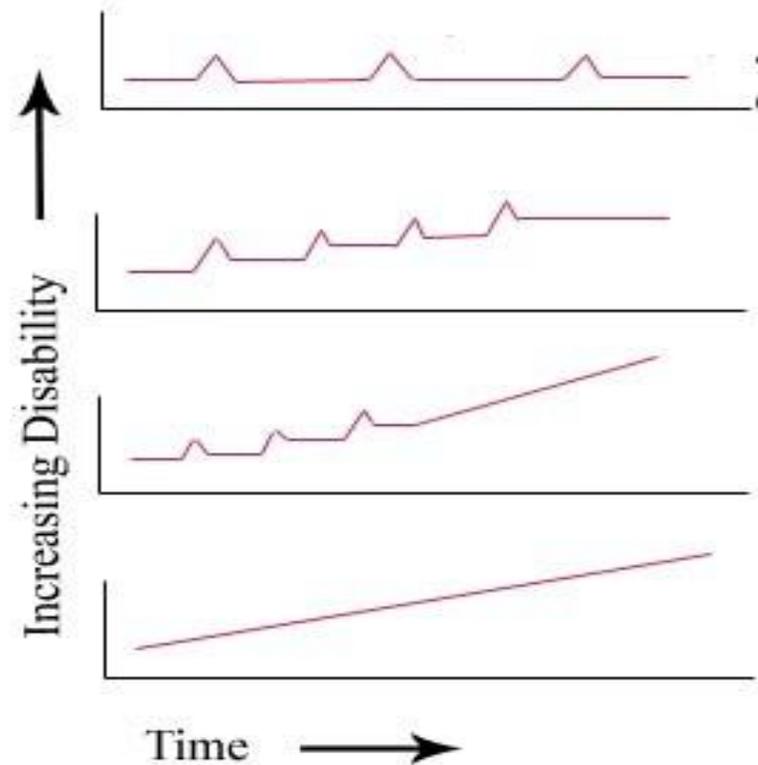
(>90% of peds MS; most common type in adults)

Secondary progressive

(begins 5-15 yrs after initial MS symptoms)

Primary progressive

(rarely seen, esp in kids)



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Diagnosing MS in Children

- Evidence of at least two separate and distinct neurologic attacks, which occur at least on month apart in different areas of the brain and/or spinal cord
- All other possible explanations must be ruled out

Diagnoses That Mimic MS

- Infection
 - Lyme disease
 - Neurosyphilis
 - PML, HIV, HTLV-1
- Inflammatory
 - SLE
 - Sjögren's
 - Other CNS vasculitis
 - Sarcoidosis
 - Behçet's disease
- Metabolic
 - Vitamin B₁₂ and E deficiencies
- CADASIL, other rare familial diseases
- CNS lymphoma
- Cervical spondylosis
- Motor neuron disease
- Myasthenia gravis



Initial Onset of Symptoms

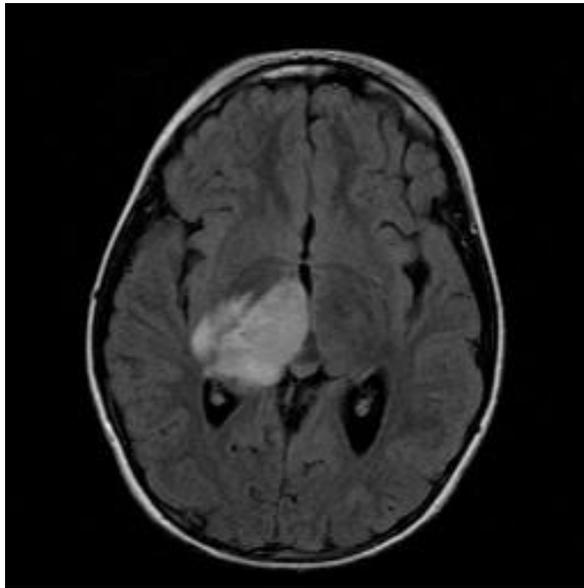
- Acute Disseminating Encephalomyelitis (ADEM)
- Clinically Isolated Syndrome (CIS)
 - Brainstem
 - Spine (Transverse Myelitis)
 - Optic Nerves (Optic Neuritis)



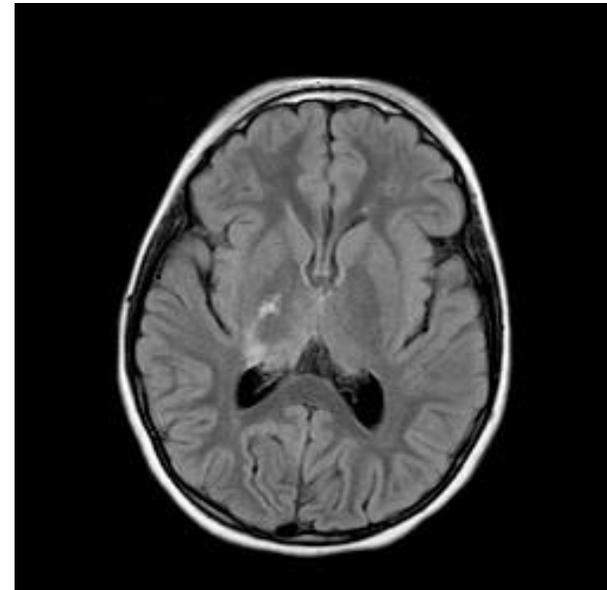
ADEM

- Prolonged encephalopathy (sick brain)
- Large Lesions on MRI- may involve brain and spine
- New onset seizure
- Recent viral or bacterial illness
- Recent immunizations
- or adverse reaction to medication
- Child is lethargic and very difficult to arouse with altered mental status
- Oftentimes, child is very sick and may require ventilation or careful monitoring in the ICU
- Long recovery and rehabilitation

ADEM



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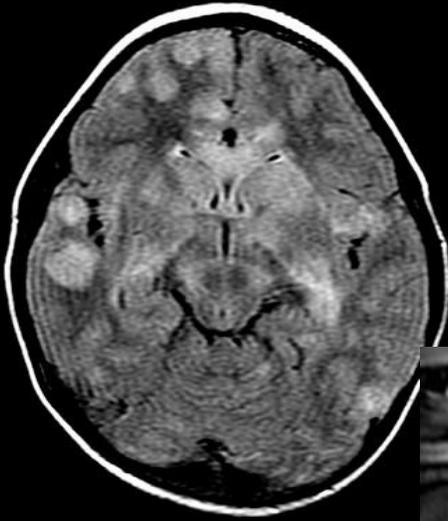
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Clinically Isolated Syndrome

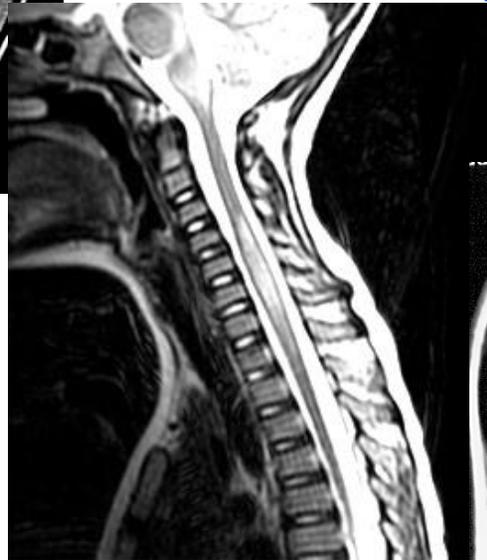
- Initial episode of CNS demyelinating symptoms
- May either be monofocal or multifocal, but **NO behavioral changes or AMS**
- Examples:
 - Optic neuritis
 - Transverse myelitis
 - Brainstem, cerebellar, and/or hemispheric dysfunction



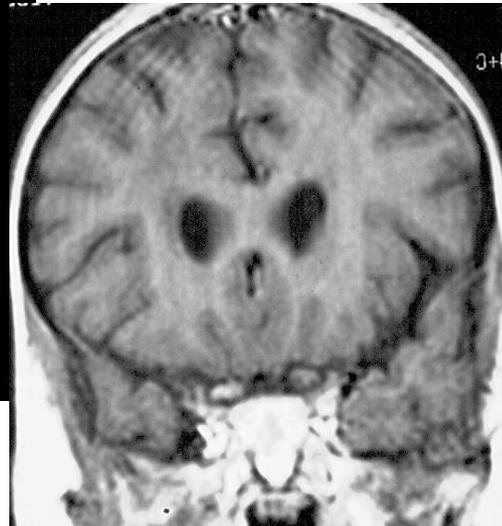
MRIs in Comparison



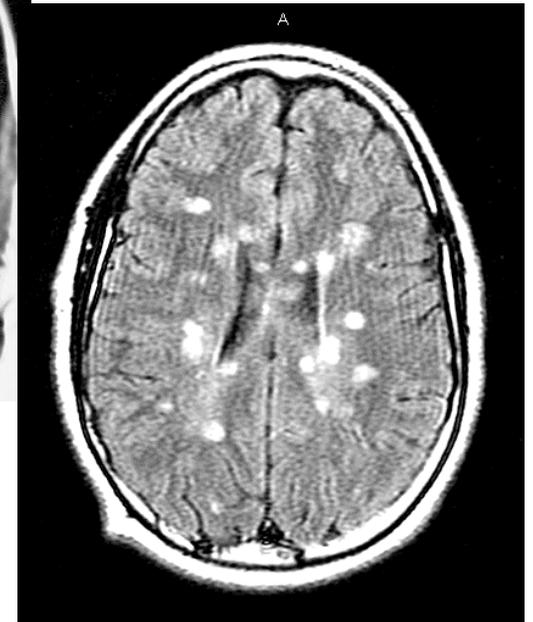
ADEM



Transverse Myelitis



Optic Neuritis



Multiple Sclerosis



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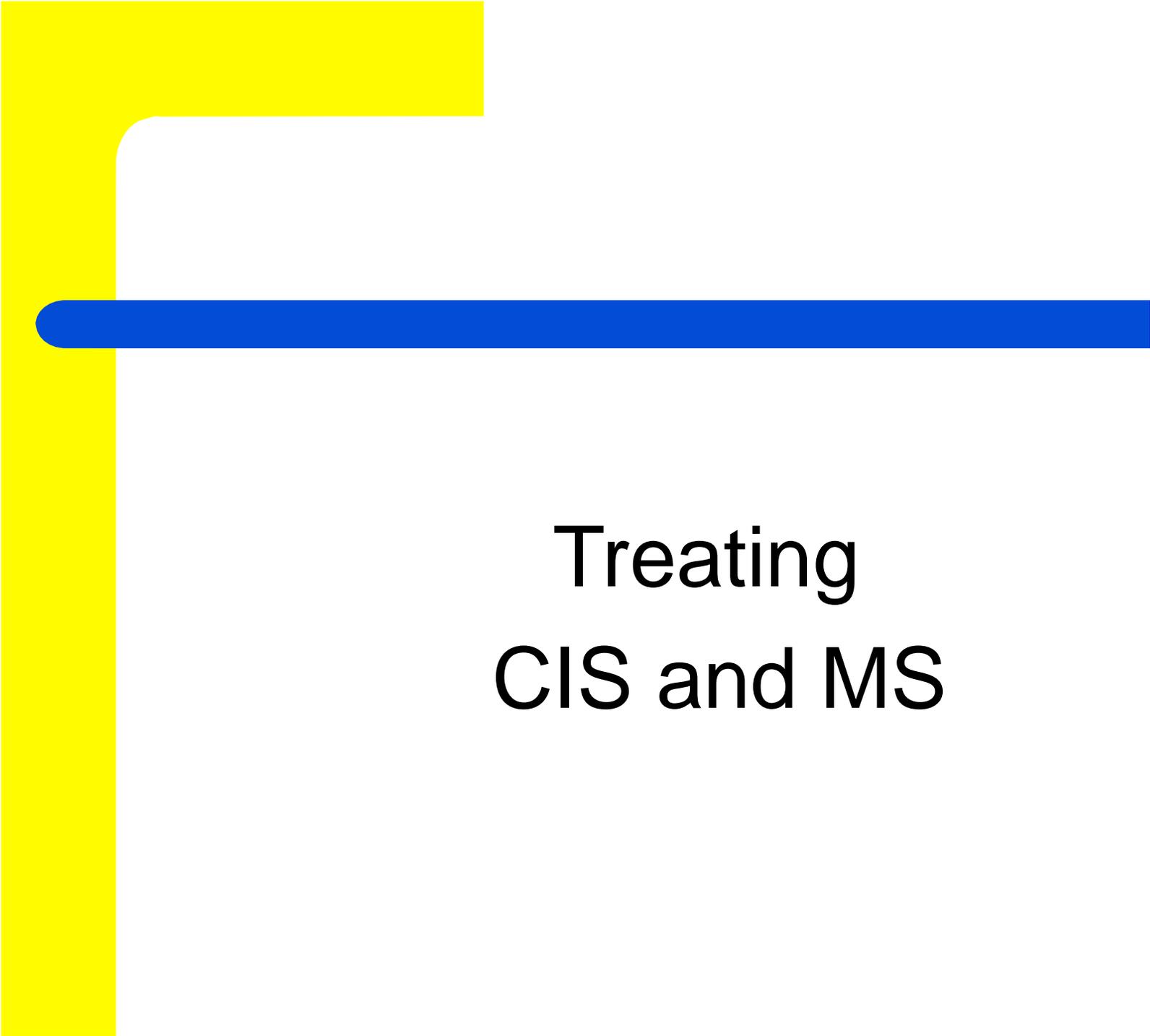
What do you tell parents and patients after first demyelinating event?

- Important distinction for prognosis
 - ~50% of CIS becomes MS
 - 10% of ADEM becomes MS

RISK FACTORS FOR MS:

- Post-puberty
- African-American ethnicity
- CIS as the initial episode
- MRI with discrete white matter or brainstem lesions
- Oligoclonal bands in CSF



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Treating CIS and MS

Treatment for Initial CIS

- High Dose Corticosteroids given over 3 to 5 days, oftentimes followed by a oral steroid taper
- Intravenous immunoglobulins (IVIg) 1-5 doses
- Plasmapheresis-5 exchanges every other day

Treatment for MS

- Treat the exacerbations
- Disease-modifying medications
- Symptom management

Treat the Exacerbations of MS

- Same treatment as CIS

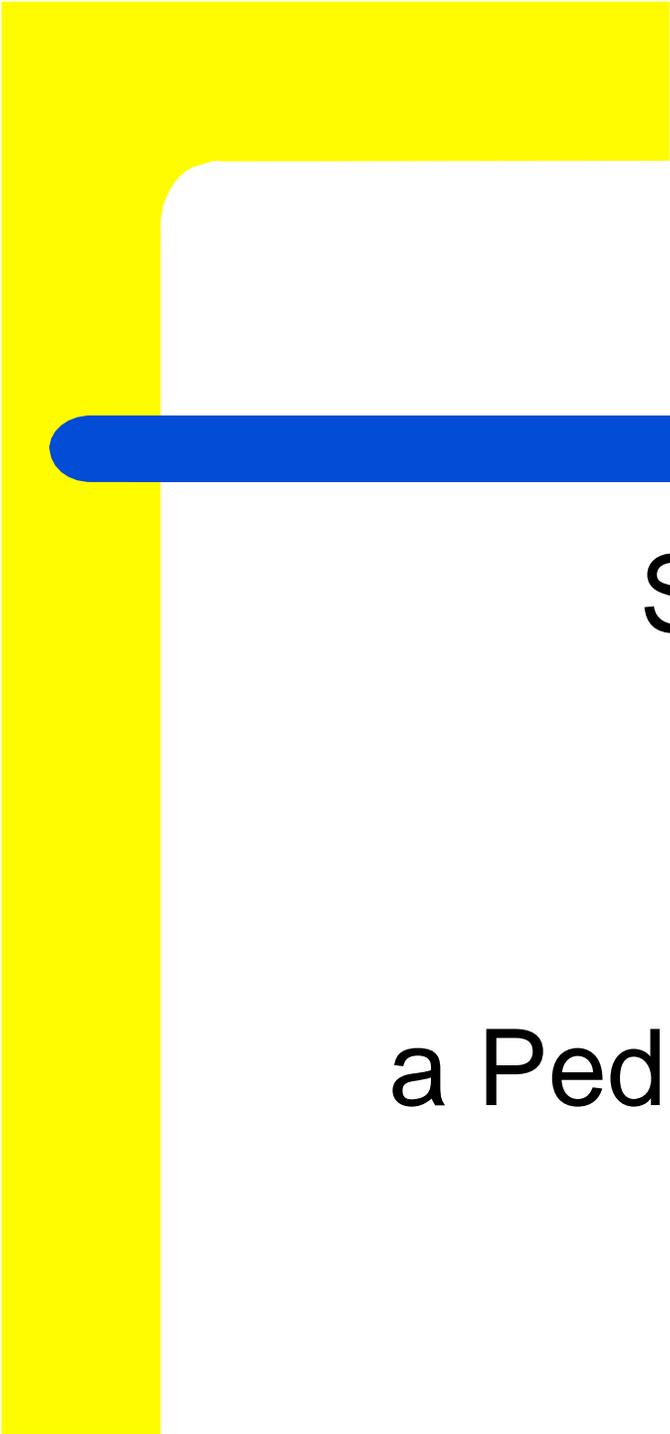
Treatment with Disease Modifying Medications in Pediatric MS

- **No FDA-approved drugs for pediatric MS**
 - Interferon β -1a (Avonex, Rebif, Plegridy)
 - Interferon β -1b (Betaseron, Extavia)
 - Glatiramer Acetate (Copaxone)
 - ★ Doses decreased for smaller patients
- Some increase in liver function tests in younger patients
- **No data on “best” drug for kids...or adults**

Big gun drugs (rarely used in kids): Tysabri, Novantrone



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Special Issues of Concern with a Pediatric MS Diagnosis



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Special Problems for Pediatric Onset MS

School

- Many patients have lower school performance following MS diagnosis
- Correlated with duration of disease

Impacts future career planning

- Need good grades to go to college and get a better job...with insurance benefits

Emotional impact

Patient
Family

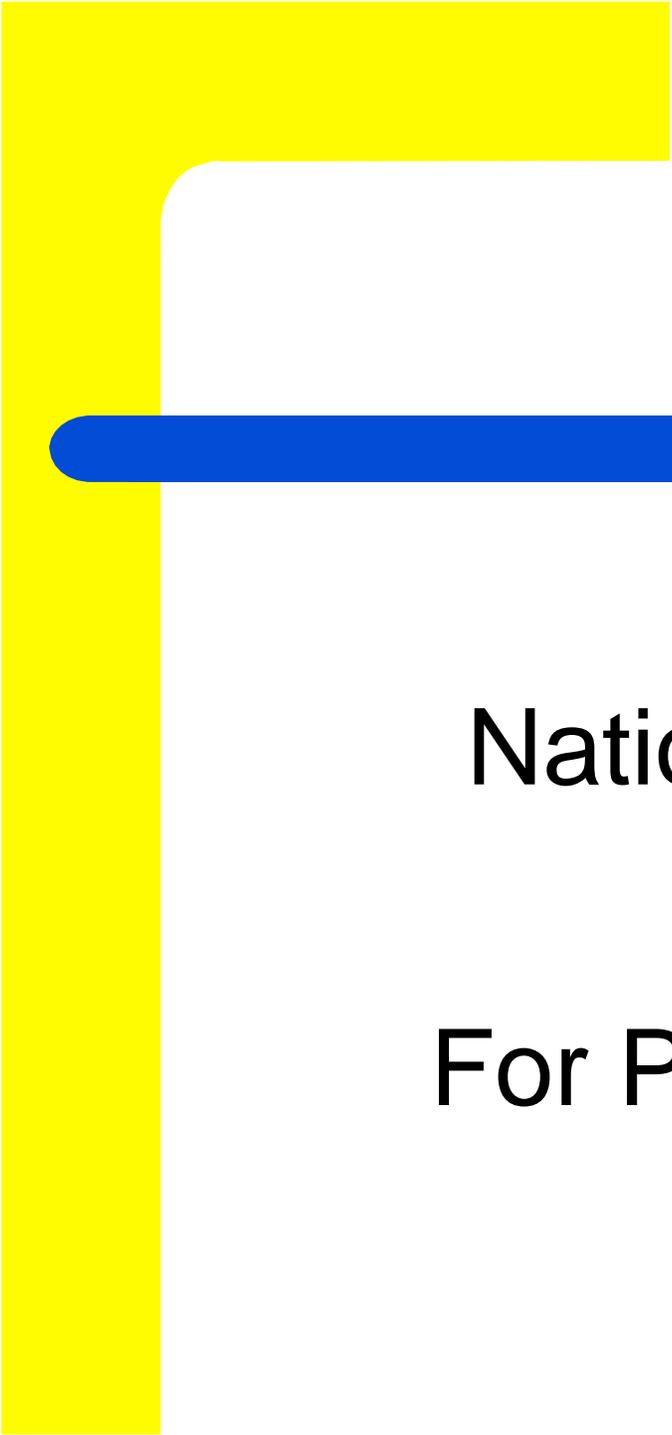


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Extensive, Ongoing Patient Education and Management

- Extensive education is needed in this area to newly diagnosed patients
 - Symptom management
 - Differentiating MS from primary care issues
 - Medications administration and side effects
 - Follow-up for labs, MRI and neurology appointments





National MS Society's Concern For Pediatric Onset MS



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National Multiple Sclerosis Society Funded Six Pediatric MS Centers of Excellence in 2006



Center for Pediatric Onset Demyelinating Disease (CPODD) at the University of Alabama at Birmingham

- Serves 8 states in the Southeast including Alabama, Georgia, Florida, Mississippi, Tennessee, North and South Carolina, and Louisiana
- Provides multi-disciplinary care for children and adolescents with MS and related demyelinating disorders



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Why the Need for Specialized Centers ?

- On-going assessment
- Research
- Referral and consultation outreach
- Long term follow-up care
- Develop a diagnostic criteria specific for children
- Comprehensive education

Services Provided To CPODD Patients

Common Service Provided To All Patients

Pediatric and Adult Neurology
Nursing Services
Neuropsychological Testing
Psychiatry

Referrals Made on Patient Needs

Physical Therapy
Occupational Therapy
Social Services
Neuro-ophthalmology
Pediatric Urology
Rehabilitation Medicine
Psychiatric Therapy



Center for Pediatric Onset Demyelinating Disease

- **Pediatric Neurologist:**
Jayne Ness, MD-PhD
- **Adult Neurology MS experts:**
Khurram Bashir, MD, MPH (UAB)
- John Rinker, MD (UAB)
- **Neuropsychologist:**
Dan Marullo, PhD
- **Neuro-ophthalmologist:**
Mike Vaphiades, DO
- **Rehabilitation Medicine:**
Drew Davis, MD;
- **Pediatric Urology:**
Anthony Hearndon, MD; David Joseph, MD
- **Pediatric Neuro-Radiology**
Dan Young, MD (Children's of AL);
- **Pyschiatry:**
Sam Rubin, MD
- **Program Coordinator:**
Sarah Middleton, MPH
- **Nurse Practitioner:**
Yolanda Harris, MSN. CRNP-AC
- **Social Work:**
Lynda Williams, MSW
- **Physical Therapy:**
Connie Cushing, PT
- **Occupational Therapy:**
Michelle Puckett, OT





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