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Diagnosis/symptom
Headache

Referring provider's initial evaluation and management can include:

- Patients with recurrent headache and a normal neurologic exam generally do not require ancillary testing.
- Brain imaging studies (MRI) are suggested for patients who have headaches that awaken them in the middle of the night, patients whose headaches begin shortly after arising from bed in the morning (i.e. positional headache), or for patients whose headaches are associated with transient neurologic deficits (e.g. hemiparesis, ophthalmoparesis, confusion).
- All patients presenting for an evaluation of headache should have a fundoscopic examination to evaluate for papilledema prior to their referral .

When to initiate referral:

- **Patients with a new severe headache of acute onset, headache with a focal neurologic deficit, or headache associated with papilledema should be referred to the Emergency Department.**
- Recurrent headache has been present for at least six months or for patients with headache associated with focal neurologic deficits.

What can referring provider send?

- Parents must keep a written headache calendar indicating the date and time of day of each headache, the duration of each attack, the severity and description of the attack, the treatment provided and response, and any causative factors (e.g. foods, activities, stressors). At least two months of clinical information must be charted by the family on the headache calendar.
- A complete list of all medications used to treat headache (both acutely or for prophylaxis) along with a list of other medications taken
- Copies of medical records regarding past evaluation and treatment of headaches
- Copies of any brain imaging films, EEG reports and relevant laboratory reports

> Additional Information:

- By following these recommended guidelines, referring physicians can provide important clinical information for further evaluation and management of patients.
- Pediatric seizure patients will be triaged according to level of acuity.



Diagnosis/symptom
Febrile Seizures

Referring provider's initial evaluation and management can include:

- Infants and toddlers less than 2 years of age with a first simple (benign) febrile seizure do not require brain imaging, EEG, or neurological consultation.

When to initiate referral:

- Children greater than 2 years of age with a first simple (benign) febrile seizure may benefit from consultation on a case by case basis.
- Children with multiple recurrences of simple febrile seizures may benefit from consultation on a case-by-case basis.
- Consultation may be considered for children with atypical (complex) febrile seizures. An atypical febrile seizure is defined as a febrile seizure lasting greater than 15 minutes, or a febrile seizure with partial onset or focal features during or after the seizure, or recurrent febrile seizures within 24 hours of the first episode.

What can referring provider send?

- Brain imaging and EEG should be deferred unless recommended by the neurologist.
- Copies of the official reports of the studies, if obtained, sent with all relevant medical records. If brain-imaging studies were interpreted as abnormal, please send films.



Diagnosis/symptom
First Afebrile Seizure

Referring provider's initial evaluation and management can include:

- An awake and asleep EEG should be obtained after a first unprovoked afebrile seizure. Prefer EEG obtained at Children's. The EEG should be scheduled at least a week after the seizure.
- An MRI scan should be scheduled if EEG shows a focal abnormality.

When to initiate referral:

- After first unprovoked afebrile seizure at discretion of referring provider

What can referring provider send?

- Awake and asleep EEG
- Send all relevant medical records and copies of the official reports of ancillary studies and the films of all brain imaging studies.
- A home videotape of seizure/spell is helpful.



Diagnosis/symptom
MITOCHONDRIAL

Diseases of the mitochondria appear to cause the most damage to cells of the brain, heart, liver, skeletal muscles, kidney and the endocrine and respiratory systems. See below for organ system and possible problems.

Brain

Developmental delays, mental retardation, dementia, seizures, migraines, strokes.

Kidneys

Proximal renal tubular wasting resulting in electrolyte imbalance

Heart

Conduction defects (heart blocks), cardiomyopathy

Liver

Hypoglycemia (low blood sugar), liver failure

Eyes

Unusual eye movements, visual loss and blindness

Ears

Hearing loss and deafness

Pancreas

Diabetes and exocrine pancreatic failure

Systemic

FTT, short stature, fatigue, intermittent air hunger

Referring provider's initial evaluation and management can include:

HISTORY

PHYSICAL EXAM

NUTRITIONAL ASSESSMENT

LABS (performed at same time):

OVERNIGHT FASTING:

- Electrolytes
- Chem panel
- AST/ALT/CK
- Amino Acids
- Acylcarnitine profile
- Lactic acid, venous
- Ammonia, venous
- Intracellular CytoQ10

URINE:

- Organic acids
- Metabolic screen

When to initiate referral:

- For ongoing management of issues specific to Mito disorder and its associated conditions or secondary disability including:
 - Feeding and nutrition
 - Communication
 - Bowel/bladder function
- Comprehensive recommendations for multiple issues related to severe disability

What can referring provider send?

- Detailed H&P, including all current interventions, therapies, and treatment
- Growth grid and any measurements to help with nutritional assessments
- Medication list
- Provide all lab results. Please submit results with initial referral.
- Provide all relevant reports and evaluations, including any brain imaging, such as MRI/CT/Ultrasound which are helpful
- Describe functional limitations and include information about child's current activities
- Indicate whether child is using any assistive devices such as braces, walker, or wheelchair

What can referring provider send?

Detailed history and physical exam, review of laboratory studies, radiographic studies (MRI, MRS, etc.)

The multi-faceted nature of mitochondrial disease benefits from a comprehensive, individualized approach.

The goal of every intervention is to enable each child to grow up within a family and community; to achieve his/her optimal independence in adult life, to insure comfort and ease of care, and to prevent secondary disabilities.



Diagnosis/symptom

Recurrent Unprovoked Seizures (Epilepsy)

Referring provider's initial evaluation and management can include:

- Awake and asleep EEG
- Schedule an MRI if EEG shows a focal abnormality.

When to initiate referral:

- Consulting neurologist will provide the primary care physician with recommendations for further evaluation and management, but will not provide principal care unless epilepsy becomes intractable.

What can referring provider send?

- Awake and asleep EEG
- Copies of all relevant records and ancillary studies and chronology of all anticonvulsant medications and results of anticonvulsant blood levels
- If seen previously by other neurologists please send copies of medical records from those specialists.
- Chronology of all anticonvulsant medications together with the results of anticonvulsant blood levels is needed.



Diagnosis/symptom
Intractable Epilepsy

Referring provider's initial evaluation and management can include:

- Some patients may become candidates for the ketogenic diet, vagus nerve stimulator or epilepsy surgery.

When to initiate referral:

- Children with intractable epilepsy generally will need to have this chronic problem managed by a neurologist who serves as the principal care provider.

What can referring provider send?

- Complete medical records including copies of the films of brain imaging studies
- Copies of EEG tracings
- A complete chronology of all previous and current therapies including blood levels, results of neuropsychological tests, results of any metabolic tests or biopsies, and reports of any neurosurgical procedures

Clinic phone: 206-987-2078. To request a consult or referral, please call the Clinical Intake Nurses at 206-987-2080 or toll free at 866-987-2080. You may fax a New Appointment Request Form to 206-985-3121 or toll free at 866-985-3121. To speak with a Seattle Children's physician for an urgent phone consultation, call the Physician Operator at 206-987-7777 or toll free at 877-985-4637.

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