

IS-2019-44
September 23, 2019

Definitions

Cunningham Panel - The purpose of the Cunningham Panel is to provide laboratory results that assist physicians in diagnosing infection-induced autoimmune neuropsychiatric disorders.

Immunoglobulin is part of your blood's plasma. It has antibodies in it to fight germs or disease.

Intravenous Immunoglobulin or IVIG is a human blood product consisting of antibodies which is used to treat immunodeficiency disorders. This therapy can help people with weakened immune systems or other diseases fight off infections.

Neuropsychiatric Disorders are those illnesses that have both neurological and psychiatric features.

PANDAS is an acronym for **Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal** infection. It is an autoimmune condition initially triggered by strep infections, which disrupts a child's normal neurologic activity. PANDAS occurs when the immune system produces antibodies, intended to fight an infection, and instead mistakenly attacks healthy tissue in the child's brain, resulting in inflammation of the brain (basal ganglia section) and inducing a sudden onset of movement disorders, neuropsychiatric symptoms and abnormal neurologic behaviors.

PANS is the acronym for **Pediatric Acute-onset Neuropsychiatric Syndrome**. This occurs when exposure to any number of infectious agent(s) triggers a misdirected immune reaction, where antibodies attack a portion of the brain, causing inflammation which disrupts a child's normal neurologic activity causing an abrupt onset of neuropsychiatric symptoms.

Plasmapheresis - A process in which the liquid part of the blood, or plasma, is separated from the blood cells. Typically, the plasma is replaced with another solution such as saline or albumin, or the plasma is treated and then returned to your body. During a plasma exchange, unhealthy plasma is swapped for healthy plasma or a plasma substitute, before the blood is returned to the body.

Moleculera Parent Survey 2018

Selected Findings for the PANDAS/PANS Interim Study

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N= 1098 Respondents

1. Costs related to provider visits
33% paid from \$5K-\$20K
15% paid from \$20K to >\$50K
2. Costs of travel to provider visits
32% paid from \$1K-\$5K; 20% paid from \$5K- >\$50K
3. Hospitalizations
29% of patients have been hospitalized at least 1 time
63% admitted in psychiatric hospitals
24% have been hospitalized 5-6 times
Mean length of stay = 46 days
4. Medication costs
68% paid from \$1K-\$10K
3% paid from \$10K- >\$50K
5. Immunotherapy
40% received immune modulating therapies
91% of those received immunoglobulins
16% paid >\$100K on IVIg
6. Adjunctive therapies
89% received these services,
55% paid from \$5K-\$25K
16% paid from \$25K->\$50K
7. Laboratory tests
47% paid from %5K- >\$50K
8. Loss of income
45% of families, one parent had to stop working
8% fired due to absenteeism
9. Insurance coverage
96% of responders had medical insurance
Less than 3% had insurance coverage for the
Cunningham Panel
10. Was the Cunningham Panel useful?
82% - helpful with obtaining diagnosis