



# Illinois Department of Insurance

## Fact Sheet

### PANDAS / PANS

September 2017

**Note:** This information was developed to provide consumers with general information and guidance about insurance coverages and laws. It is not intended to provide a formal, definitive description or interpretation of Department policy. For specific Department policy on any issue, regulated entities (insurance industry) and interested parties should contact the Department.

This fact sheet provides information regarding the newly required coverage of treatment for individuals diagnosed with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (“PANDAS”) and pediatric acute onset neuropsychiatric syndrome (“PANS”).

The State of Illinois is the first state in the country to protect families addressing a PANDAS/PANS diagnosis by requiring insurance providers to cover treatments of PANDAS/PANS. Illinois is leading the way in addressing PANDAS/PANS and making medical treatment attainable for Illinois families.

### Illinois Law

Effective July 18, 2017, amended Illinois law 215 ILCS 5/356z.25 requires all group or individual policies of accident and health insurance or managed care plans that are **amended, delivered, issued or renewed after July 18, 2017**, to provide coverage for treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome (“PANDAS/PANS”), including but not limited to, the use of intravenous immunoglobulin therapy (“IVIG”).

### Commonly Asked Questions

#### **Who is covered?**

Participants enrolled in a group or individual policy of accident and health insurance or managed care plan that is amended, delivered, issued, or renewed after July 18, 2017, and who are diagnosed with PANDAS/PANS shall receive coverage for treatment.

#### **What is Covered?**

The new law requires coverage of treatment for PANDAS/PANS, including, but not limited to, the use of IVIG.

#### **Can insurers deny claims for PANDAS/PANS treatment based on medical necessity?**

Insurance providers may still deny claims subject to the exclusions set out in your policy, but they cannot deny IVIG treatment as medically unnecessary since the statute specifically provides for IVIG. Please see your policy terms for specific coverage information.

**Can insurers deny claims for PANDAS/PANS treatment based on the experimental and/or investigational nature of treatment?**

Insurance providers may still deny claims subject to the exclusions set out in your policy but they cannot deny IVIG treatment as experimental and/or investigational since the statute specifically provides for IVIG. Please see your policy terms for specific coverage information.

**Is PANDAS/PANS treatment covered when treatment is provided out of state?**

The treatment of PANDAS/PANS by out of state providers is based solely on the terms of your insurance policy, which is similar to out of state treatment for any condition.

**Since insurers must cover IVIG for PANDAS/PANS, is IVIG free?**

No. Insurance companies are still able to use cost-sharing practices to address the price of treatment. Cost sharing for PANDAS/PANS treatment may include, but is not limited to, copays, deductibles, and/or coinsurance as established by the applicable policy terms. Please see your policy terms for specific coverage information.

**Do you have to be diagnosed with co-occurring primary immune deficiency to receive treatment for PANDAS/PANS?**

No. This statute does not require a diagnosis of primary immune deficiency to receive coverage for treatment if there is a PANDAS/PANS diagnosis.

**Does this Illinois law affect the ability of participants with co-occurring common variable immune deficiency (“CVID”) to receive IVIG?**

No.

**Does the Illinois law have a cut-off age for a participant to receive coverage for the treatment of his or her PANDAS/PANS diagnosis?**

No. If an individual is diagnosed with PANDAS/PANS, such participant’s health insurer must provide coverage of treatment regardless of the participant’s age. The law leaves the determination of appropriate medical diagnosis to the medical provider.

**Will the Illinois law apply to an Illinois resident who is covered by an insurance policy issued in another state?**

If the Illinois resident is a member of an HMO written outside of Illinois and the HMO has established a provider network in Illinois, such HMO is subject to this law; otherwise, this law does not apply to out-of-state policies. To determine if your HMO coverage is required to provide coverage for PANDAS/PANS treatment, contact your HMO or check your certificate of coverage.

**Does this law apply to insurance provided to State of Illinois employees and/or State of Illinois retirees?**

Yes. The law requires plans offered by the State of Illinois through its group health insurance to comply.

**The law applies to:**

- All group and individual policies of accident and health insurance or managed care plans that are amended, delivered, issued, or renewed **after July 18, 2017** in the State of Illinois;
- Insurers for Illinois state, county, and municipal employees; and
- Insurers provided through the Illinois School Code, the Limited Health Service Organization Act and the Voluntary Health Services Plans Act.

**The law does NOT apply to:**

- Self-insured, non-public employers;
- Self-insured health and welfare plans, such as union plans; and
- Insurance policies or trusts issued in other states.

**Federal Law**

There is no current federal law addressing insurance coverage for treatment of PANDAS/PANS. The Department of Insurance will analyze and regulate as required any new federal law enacted regarding the coverage of treatment for PANDAS/PANS.

**For More Information**

Call our Office of Consumer Health Insurance at (877)527-9431  
or visit us on our website <http://insurance.illinois.gov>