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November 14, 2019

Delegate Charles Sydnor  
House Office Building, Room 306  
6 Bladen Street  
Annapolis, MD 21401

**Re: House Bill 15 – Health Insurance – Pediatric Autoimmune Neuropsychiatric Disorders – Coverage**

Delegate Sydnor,

This letter comes as a result of a workgroup convened by the Maryland Insurance Administration (MIA) to study the gaps in coverage for PANDAS, as well as the gaps in provider and consumer knowledge about the coverage, and determine what actions may be needed to ensure that PANDAS patients receive coverage for medically necessary treatment.

Please find the MIA's report below.

**Legislative History**

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) are conditions that cause neuropsychiatric symptoms in children. Currently, there is no mandate to cover treatment specific to PANDAS and PANS. The Pediatric Autoimmune Neuropsychiatric Disorders – Coverage bill was introduced as HB 15 during the 2019 Maryland General Assembly Session by Del. Sydnor. HB 15 was given an unfavorable report by the House Health and Government Operations Committee (HGO) and was withdrawn by the plan sponsor. As proposed, this bill would provide a new mandated benefit requiring an insurer, nonprofit health service plan, or health maintenance organization that provides hospital, medical, or surgical benefits to provide coverage for the medically necessary diagnosis, evaluation, and treatment of PANDAS and PANS including the use of intravenous immunoglobulin therapy.

**Maryland Department of Health Report**

The Maryland Department of Health (MDH) conducted stakeholder meetings, at the request of HGO Chairwoman Shane Pendergrass, related to PANDAS in September and October of 2018. MDH submitted a report on the meetings to the General Assembly in January of 2019. The consensus stakeholder recommendations were:

- Raising awareness of PANDAS among school staff, including school nurses;
- Raising awareness of PANDAS among parents/guardians;
- Raising awareness of PANDAS among providers; and
- Raising awareness of PANDAS among the general public.

### **Maryland Insurance Administration Workgroup**

Following the 2019 Legislative Session, the MIA established an informal work group (Workgroup) at the request of Delegate Bonnie Cullison. The goals of this Workgroup are, as they relate to PANDAS, to pinpoint the gaps in coverage, as well as the gaps in provider and consumer knowledge about the coverage, and determine what actions may be needed to ensure that PANDAS patients receive coverage for medically necessary treatment. The Workgroup held public meetings on June 6, June 26, and July 24, 2019 to gather information and insight into the issues affecting consumers and providers. The public meetings provided a venue for stakeholders and other interested parties to voice concerns about the current state of insurance coverage for PANDAS related treatments, discuss the proposed legislation, and provide any additional information related to the coverage and provider treatment of PANDAS. A phone number for interested parties to call in was provided for each meeting. The MIA also sent notice of the Workgroup and public meetings to the list of those who testified on the bill during the legislative session, people who had expressed interest to the MIA, and those who identified themselves as stakeholders or interested persons. The MIA also created a quick link on its website for the PANDAS Workgroup and included an email address in order to solicit comments from stakeholders and the public.

The first meeting was held on June 6<sup>th</sup>. The Workgroup heard testimony and comments from parents of PANDAS patients, a physician who treats PANDAS, and a representative of a carrier. The second meeting was held on June 26<sup>th</sup>. The Workgroup heard testimony and comments from representatives of 3 carriers, as well as a health care provider who treats PANDAS, and parents of PANDAS patients. The third, and final, meeting was held on July 24<sup>th</sup>. The Workgroup heard testimony and comments from parents of PANDAS patients and representatives of carriers. In addition to the public meetings, the MIA received written testimony from PANDAS activists, one provider, and one carrier. The MIA reached out to representatives of the Maryland Chapter of the American Academy of Pediatrics, but they declined to participate in the meetings.

### **PANDAS Basics**

There were numerous topics addressed in the oral and written testimony provided at the public meetings. These included the effects of PANDAS on a family, the definition of PANDAS, the lack of PANDAS knowledge by providers and consumers, a lack of a diagnosis code in the current version of the Statistical Classification of Diseases and Related Health

Problems (ICD) for PANDAS, and the complications associated with medical treatment for PANDAS. The treatment-related topics included the availability of providers generally and in-network providers specifically, the treatment options for PANDAS, and the insurance coverage of treatment for PANDAS.

### *Definition*

PANDAS was not specifically defined in HB 15. The National Institute of Mental Health has a brochure and webpage on PANDAS that says:

PANDAS is short for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. A child may be diagnosed with PANDAS when:

- [Obsessive-compulsive disorder \(OCD\)](#), tic disorder, or both suddenly appear following a streptococcal (strep) infection, such as strep throat or scarlet fever.
- The symptoms of OCD or tic symptoms suddenly become worse following a strep infection. The symptoms are usually dramatic, happen “overnight and out of the blue,” and can include motor or vocal tics or both and obsessions, compulsions, or both. In addition to these symptoms, children may become moody or irritable, experience anxiety attacks, or show concerns about separating from parents or loved ones.

### *Treatment*

The Workgroup received written testimony and also heard testimony that there is general agreement among PANDAS researchers and clinicians that the initial treatment for PANDAS is antibiotics. Antibiotics may be used prophylactically as well. Antibiotics treat the strep infection causing the symptoms. Steroids are also used as an early treatment. Neuropsychiatric symptoms may be managed with medications for obsessive-compulsive symptoms, cognitive behavioral therapy, or both.

In more advanced cases, treatment with intravenous immunoglobulin (IVIG) therapy may be required. IVIG is a blood product, administered intravenously, and made from antibodies that have been taken from the blood of many healthy donors. Rituximab is another treatment for more advanced cases. Rituximab is a drug that is administered intravenously.

The Workgroup heard extensively at the public meetings and in written submissions that carriers do not adequately cover IVIG. Rituximab was mentioned less often, but the Workgroup heard of difficulty obtaining coverage for the treatment.

### *Appointments*

There was testimony from parents that it is very difficult to find a health care provider to treat their children with PANDAS. Pediatricians who are familiar with PANDAS will treat appropriately with antibiotics and steroids, but many pediatricians are not familiar with PANDAS. Not all providers are familiar with the diagnosis, and some providers disagree that PANDAS is a valid diagnosis.

There are pediatric neurologists who treat PANDAS in the District of Columbia, but there are none in Maryland. The physicians in the District of Columbia do not participate in the provider panels for any insurance carriers. Providers in New York and West Virginia may participate on some carriers' national provider panels, but are not easily accessible. Treatment by a pediatric neurologist is necessary in more advanced cases, for which IVIG treatment is needed. There may also be a lengthy delay in getting an appointment with a pediatric neurologist who treats PANDAS.

Due to the lack of providers in Maryland who participate in insurers' provider panels, authorization for an out-of-network referral may be required to obtain reimbursement for some health plans with closed panels. For patients with PPO coverage, parents could seek an authorization to see the out of network provider under in-network coverage. If the carrier authorizes the referral, the amount of reimbursement may be less than the provider's billed charges. The patient's family is typically responsible for paying the extra amount not covered by insurance.

The Workgroup heard from parents that the costs of IVIG were typically around \$10,000, which had to be paid by the parents directly to an out of network provider. If the carrier approved treatment, the parents might be reimbursed, but in a lower amount. Children with PANDAS typically required multiple IVIG treatments. Rituximab could cost \$25,000. Due to the lack of in-network providers, parents were generally required to pay for treatments and then file a claim for reimbursement.

The Workgroup heard from one parent whose child had been treated with rituximab. Most of the testimony centered on coverage for IVIG.

### ***Provider Knowledge***

The Workgroup heard testimony from individuals who did not feel that medical providers as a whole are familiar with PANDAS. Some parents reported having a diagnosis made by a pediatrician or other health care provider, but being disbelieved or having trouble obtaining treatment from other health care providers. There were reports of providers who are hostile to the idea of a PANDAS diagnosis.

In some cases, pediatricians knew of PANDAS, and were willing to diagnose and treat with antibiotics, but were unwilling or lacked the expertise to treat with IVIG or rituximab.

There was also testimony that facilities are reluctant to treat PANDAS patients. One parent stated that the carrier had approved IVIG infusion treatment, but a facility could not be found that was willing to administer the infusion. In one instance, a home infusion was not safe for the patient. In some cases, parents said that they were advised to tell hospital staff that their child had autoimmune encephalitis rather than PANDAS.

There was testimony from a physician who treats PANDAS with IVIG that difficulty in obtaining approval for IVIG treatment was a factor in keeping physicians from participating in provider panels of carriers.

The ICD-10 does not have a diagnosis code for PANDAS. The Workgroup was told that there will be a diagnosis code in ICD-11.

### *Consumer Knowledge*

In general, the parents who testified were very knowledgeable about PANDAS and the availability of treatment. Testimony from parents primarily involved one carrier group. There was variation in the level of understanding of insurance products and regulation.

The MIA staff explained the differences between the health maintenance organization (HMO) plans, which often restricted coverage to plan providers, and the preferred provider organization (PPO) plans, which cover services received from non-plan providers, but at a reduced level. The MIA made clear at the public meeting that the MIA only regulates fully insured plans and not self-insured or self-funded health plans. This was revealed to be a gap in consumer knowledge for PANDAS patients, although the MIA notes that this particular distinction exists across all types of health plans and patients.

Based on testimony, parents often learned of PANDAS after their child had been treated for behavioral disorders unsuccessfully. There were parents who feared that the delay in diagnosis could have a permanent effect on their children. Wider education of the public concerning PANDAS could increase early diagnosis.

### **The MIA Workgroup Questions**

The MIA Workgroup posed the following questions to carriers:

1. What are the policies and criteria to determine if IVIG or Rituximab will be covered to treat PANDAS that has not responded to antibiotics?
2. How are the criteria developed?
3. How many requests for authorization are received, and how many are approved?
4. What medical specialty is considered appropriate to make a decision to approve or disapprove a request?
5. How many physicians are in the network to treat PANDAS? How many facilities will provide infusion or other services to treat PANDAS?
6. How many requests for referrals under § 15-830 of the Insurance Article are received? How many are granted?
7. What is the estimated prevalence of PANDAS?

### **Coverage Criteria**

The MIA Workgroup was told that due to a lack of ICD-10 code for PANDAS, it was difficult to identify cases in which PANDAS was the condition being treated.

The carriers all stated that antibiotics and steroids prescribed by pediatricians would not require authorization and would be covered. Behavioral health treatment for tics and obsessive/compulsive thoughts was also widely covered.

At the June 26, 2019 meeting of the Workgroup, one carrier stated that IVIG for PANDAS was covered under the medical necessity criteria. One carrier stated that cases were individually reviewed, and that both approvals and denials for IVIG were found in their research. The other carriers stated that their criteria did not permit coverage of IVIG for PANDAS.

Carriers that did not cover IVIG for PANDAS stated that their health benefit plans did not cover unproven treatments. Medical necessity criteria for IVIG allowed coverage only when the treatment was proven effective for treatment of a medical condition. Carriers did not dispute the experience of the parents who testified that IVIG was effective for their children, but did dispute that there was an expert consensus that IVIG was an effective treatment for PANDAS.

Carriers are required by § 15-123 of the Insurance Article to review emerging medical treatments for coverage. The review should be conducted annually. Several carriers stated that they would conduct a review based on the evidence presented at the meetings.

A pediatric neurologist who treats PANDAS with IVIG testified regarding examples of medical necessity criteria from carriers. He vehemently disputed the assertion that IVIG had not been adequately proven an effective treatment for PANDAS, and provided documentation of IVIG's effectiveness. The journal articles were posted on the MIA's website.

At the July 24, 2019 meeting, one carrier representative stated that their criteria were being updated to allow consideration of IVIG for PANDAS, and that a dedicated case manager would be available for PANDAS cases. Prior authorization for IVIG to treat PANDAS would still be required. An authorization decision would not be based on considering IVIG an unproven treatment.

### **Other States**

The MIA sent an inquiry to other states through the National Association of Insurance Commissioners about proposed or enacted mandates for coverage of treatments for PANDAS. Minnesota, Maine, and Illinois responded with copies of their legislation. The MIA also received copies of bills introduced in Delaware and Arkansas.

The more recent Illinois bill, Public Act 101-0488, specifies that the diagnosis code for autoimmune encephalitis should be used for PANDAS until there is a code specific to PANDAS. The Maine bill states that coverage may not be excluded due to the diagnosis of autoimmune encephalopathy or autoimmune encephalitis. The addition of diagnosis code information to the legislation was considered necessary to ensure that the mandate could be enforced given the current lack of a specific code.

In general, the states that have considered or passed legislation would mandate the coverage of IVIG in addition to antibiotics, steroids, and behavioral health care services to treat PANS and PANDAS.

## **Conclusions**

The objectives of this Workgroup were to pinpoint the gaps in PANDAS coverage, as well as the gaps in provider and consumer knowledge about the coverage, and to determine what actions may be needed to ensure that PANDAS patients receive coverage for medically necessary treatment. As a result, carriers have generally become more aware of the issues being faced by those affected by PANDAS and are taking affirmative steps to resolve certain issues involving treatment options. Additionally, the MIA has received less PANDAS complaints since the conclusion of the Workgroup.

With regard to next steps, the MIA is not making any specific coverage recommendations to the General Assembly, but rather intends for this report to inform any potential legislative decisions. That being said, the MIA concurs with the MDH report submitted in 2019 that additional education to inform key groups about PANDAS would be beneficial and increased awareness would help with early identification of PANDAS cases so that treatment could begin.

The MIA further recommends that the following should be considered by the General Assembly when contemplating legislation:

- If coverage of PANDAS treatments is mandated, then it is likely that additional providers will be willing to participate in provider panels. Currently, the lack of in-network providers poses a significant barrier to treatment. Out-of-network providers may also bill families for the amount not paid by insurance coverage beyond copays and deductibles.
- Treatments for PANDAS cover a range of services, and many treatments are routinely covered.
- IVIG as a treatment for PANDAS is increasingly being covered based on scientific review, but there is no agreement among carriers as to whether it has been proven effective according to their standards.
- Carriers will want to require prior authorization of IVIG to ensure that it is medically appropriate even after IVIG can no longer be denied as unproven.
- There is currently no ICD-10 code to specify PANDAS or PANS as a diagnosis. Legislation should specify a diagnosis that can be used on a claim to which any mandate would apply.
- If coverage of IVIG or other treatments for PANDAS is considered a new mandate, the State may be required to defray the costs under the Affordable Care Act, to the extent the mandate applies to non-grandfathered plans in the individual and small group markets.

Should you have any questions, please do not hesitate to contact me.

Sincerely,

Al Redmer, Jr.  
Insurance Commissioner

**Cc: Delegate Bonnie Cullison  
Lisa Simpson, Staff Counsel, House Health & Government Operations Committee**