

**BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA**

In the Matter of:

CLAIMANT,

VS.

SAN GABRIEL/POMONA REGIONAL CENTER,

Service Agency.

OAH No. 2019120201

DECISION

Carmen D. Snuggs, Administrative Law Judge, Office of Administrative Hearings (OAH), State of California, heard this matter on January 10, 2020, in Pomona, California.

Claimant was represented by his mother.¹

Daniel Ibarra, Fair Hearings Specialist, represented San Gabriel/Pomona Regional Center (Service Agency or SGPRC).

¹ Claimant and his parents are identified by titles to protect their privacy.

Oral and documentary evidence was received. The record was held open until January 21, 2020, to allow Claimant to file with OAH and serve on the Service Agency, a copy of a video on a flash drive depicting Claimant on August 17, 2018. Claimant timely submitted the flash drive, which was marked and admitted into evidence as Exhibit I.² The record was closed and the matter was submitted for decision on January 21, 2020.

ISSUE

Shall SGPRC be responsible for reimbursing Claimant's family the cost of Claimant's monthly Blue Shield of California (Blue Shield) medical insurance premium?³

EVIDENCE RELIED UPON

Documentary: Service Agency's exhibits 1-8 and 10-11; Claimant's exhibits A-I.

Testimonial: Giselle Salas, SGPRC Manager of Transitional Services; Lisa Berry Blackstock, Patient Advocate; and Claimant's mother.

² Mr. Ibarra asserted at the hearing that the Service Agency did not object to the video.

³ Claimant's monthly premium was \$422.36 when Claimant submitted his Fair Hearing Request, however, Claimant's mother asserted that she was notified by Blue Shield that it would increase the premium in the near future. She was unaware of the increased premium amount.

FACTUAL FINDINGS

Jurisdictional Matters

1. Claimant is a 16-year old consumer of SGPRC based on his qualifying diagnosis of Autism Spectrum Disorder. In 2017, he received a diagnosis of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus (PANDAS) syndrome. Claimant lives with his parents and older sister. Claimant's primary insurer is Blue Shield of California, and he is secondarily insured by Medi-Cal.

2. On September 23, 2019, Claimant's mother requested that SGPRC reimburse Claimant's family \$400 per month for Claimant's Blue Shield medical insurance premiums. Claimant's Blue Shield providers have prescribed intravenous immunoglobulin (IVIG) treatments, which cost \$10,000 each administration, to address Claimant's PANDAS syndrome.

3. On October 23, 2019, SGPRC sent a letter to Claimant's mother indicating that it denied Claimant's request.

4. On November 21, 2019, a Fair Hearing Request on Claimant's behalf was submitted to the Service Agency, which appealed the denial of the request for reimbursement.

5. On December 11, 2019, the parties participated in an Informal Conference to discuss the matter. At that meeting, Claimant's mother asserted that PANDAS is a rare disorder and Claimant's treating physicians do not accept Medi-Cal; Medi-Cal does not cover IVIG treatments; the IVIG treatments have helped with Claimant's aggression and maladaptive behaviors; and when the IVIG treatments "wear off," Claimant's behaviors increase. (Ex. 10, pp. 1-2.) Claimant's mother further asserted

that Claimant was eligible for Medi-Cal and provided her 2018 tax return. SGPRC upheld its decision to deny reimbursement.

Request for Reimbursement

6A. Claimant's medical history is extensive and complicated, and includes irritable bowel syndrome, interstitial cystitis, encephalopathy, tachycardia, and genetic mutations. In July 2017, Claimant experienced an abrupt onset of episodes of rage with violent behavior, obsessive compulsive disorder, and tics, all of which are related to PANDAS. Claimant has verbally and/or physically assaulted his family, his therapist, and other individuals. Between November 24, 2017, and December 19, 2019, Claimant was taken to the hospital 29 times and treated for aggressive behavior and various medical conditions. On August 17, 2018, he was taken to the hospital three times when his body involuntarily contorted, he experienced severe spasms over his entire body, and he appeared to be suffocating. On one occasion, when Claimant displayed aggressive violent behavior, it took six adult men to restrain him. Claimant's maladaptive behavior required his removal from school.

6B. Due to Claimant's condition, he is unable to focus, or sit still for more than two minutes at a time without yelling at others to repeat words, or engaging in repetitive motions, aggressive pacing, or aggressive behavior. He also becomes upset with changes in his routine or environment.

7. On May 17, 2019, Nicolas Phielipp, M.D. of the University of California Irvine (UCI) Parkinson's and Movement Disorders Program examined Claimant whose chief complaint, at that time, was abnormal spontaneous movements. Dr. Phielipp noted in his progress notes that Claimant suffered significant behavioral changes over the past two years, he began receiving IVIG treatment in June 2018, and had continued

IVIG treatments as a maintenance therapy due to its perceived benefits. Dr. Phielipp determined that Claimant suffered from “an early frameshift variant in the X-linked gene GRIA3, which encodes for a NMDA glutamate receptor, and also a variant of unknown significance in the FARSF gene.” (Ex. C, p. 3.) He recommended that Claimant undergo a consultation at the metabolic clinic at Children’s Hospital of Orange County, and that Claimant continue with IVIG infusions and Chlorpromazine because the treatment appeared to be beneficial to Claimant.

8. On May 26, 2019, Sajjad A. Yacoob, M.D., Claimant’s primary pediatrician since January 24, 2019 and the Medical Director of Ambulatory Care at Children’s Hospital Los Angeles, wrote a letter explaining that Claimant had been very high functioning but after his PANDAS diagnosis, his aggressive and OCD behavior has prevented him from engaging in meaningful interactions with his family and friends. Dr. Yacoob also asserted that Claimant takes multiple medications to control his behavior and aggression and is under the care of multiple specialists. He further contended:

The **only** treatment that I have witnessed firsthand that ameliorates and even controls some of his behavior has been IVIG. Two times in the last [five] months he has received IVIG and each time I note a marked improvement in his behavior, OCD behavior, his aggressiveness and willingness to interact meaningfully with others. While not eliminating his behaviors, these treatments are far more effective than any medications he currently takes (though they help) and are valuable to help his family, friends and caregivers have some respite and recover from the stress of

his constant care. The only effective treatment for [Claimant] (and his family) currently is IVIG on a regular schedule[.] I advocate strongly that this be covered for him.

(Ex. D, p. 1, emphasis in original.)

9A. On July 18, 2019, Stephanie Young, LMFT of Stephanie Young Consultants performed a Whole Person Assessment of Claimant at SGPRC's request. She prepared a Whole Person Assessment report (Ex. 5) and noted Claimant's history of inappropriate social interactions due to autism spectrum disorder, such as invading others' personal space and interrupting others' conversations. She acknowledged that in 2017, Claimant engaged in unprovoked violent acts, his self-care skills deteriorated, and he exhibited obsessive compulsive symptoms, tics, reduced mobility, and dysautonomia responses consisting of pupil dilation, facial pallor, increased sweating, tachycardia, and quivering muscles. She further acknowledged Claimant's PANDAS diagnosis.

9B. Following her interviews of Claimant, his family, and his behaviorists, her review of Claimant's medical records, and communication with Claimant's SGPRC Service Coordinator, Ms. Young made the following recommendations: 1) continued two-to-one in-home support from providers who understand Claimant's PANDAS diagnosis and needs related to autism, and who are highly trained in responding to volatile and aggressive behaviors which occur suddenly and without provocation; 2) up to three-to-one support for Claimant whenever he rides in a vehicle to address concerns for Claimant's engagement in violent behaviors when riding in a vehicle; 3) at least three-to-one support when Claimant accesses the community due to his unpredictable aggressive and wandering behaviors; 4) continuation of IVIG treatments if deemed appropriate/necessary by Claimant's physicians; and 5) crisis team support.

10. SGPRC currently funds 354 hours per month for respite services for Claimant with Home Care Help, 130 hours per month of extended day through California Respite Care, and 96 hours per month of crisis intervention services. In addition, SGPRC recently authorized 40 hours per month of total programs support to address any behavioral issues that arise while Claimant is transported to medical appointments.

11. Since June 3, 2019, SGPRC has reimbursed Claimant \$800 per month for medical advocacy services provided by Soul Sherpa Patient Advocacy Services (Soul Sherpa). According to the June 3, 2019 Addendum to Claimant's Individual Program Plan (IPP), the reimbursement for Soul Sherpa's services was authorized for the purpose of "developing a cohesive medical and treatment program with specific goals and treatments to be identified quarterly." The services were provided to support Claimant's IPP goal for Outcome #2, namely, maintaining good health and having yearly medical exams to minimize the risks of medical issues. (Ex. 3, p. 2.).

12A. Claimant's June 3, 2019 IPP Addendum, Under Outcome #2, "supports needed from Claimant's family," states:

[¶] . . . [¶]

e. Parents will work with Soul Sherpa to identify a primary doctor who would be responsible for overseeing [Claimant's] specialty care and have Blue Shield cover that doctor's services.

f. Parents will work with Soul Sherpa to identify and coordinate plans of care from necessary specialists

[Claimant] needs for his presentation of unique and challenging conditions.

[¶] . . . [¶]

h. Parents and Soul Sherpa will coordinate Michael's specialty evaluation for Dysautonomia with POTS involvement. They will advocate for treatment of autoimmune issues with IVIG . . . infusions.

i. Parents and Soul Sherpa will seek insurance reimbursement for thousands of dollars parents have already paid on [Claimant's] behalf due [to] Blue Shield's denial [of coverage].

j. Parents and Soul Sherpa will request a state hearing with an administrative [law] judge to present evidence and argue the case [on] behalf of [Claimant] if Blue Shield continues to refuse reimbursement.

(Ex. 3, p. 3.)

12B. Under the category "support needed from service agencies," Claimant's IPP indicates Claimant's medical coverage will be provided by private insurance, Medi-Cal or other generic resources.

13. Giselle Salas is SGPRC's Manager of Transitional Services. She contended that the Service Agency denied Claimant's request for reimbursement because the Service Agency is already reimbursing Claimant's parents \$800 per month for Soul Sherpa to advocate for Blue Shield to cover Claimant's IVIG treatments.

14. SGPRC's Purchase of Service Policy prohibits SGPRC from purchasing services and supports for consumers where generic resources, such as Medi-Cal, are available. Ms. Salas contended that SGPRC is prohibited from reimbursing Claimant for the cost of the Blue Shield premiums because Claimant is eligible for Medi-Cal.

15. Lisa Berry Blackstock is the owner of Soul Sherpa. She has worked with Claimant and his family since the Fall of 2018 and has assisted Claimant with getting a proper diagnosis for his medical conditions, the proper care, and insurance coverage for his treatment. Ms. Blackstock explained that Blue Shield pays for 80 percent of Claimant's medical costs and Medi-Cal pays 20 percent. According to Ms. Blackstock, PANDAS is a new and complex diagnosis, and Blue Shield initially would not cover Claimant's IVIG treatments. However, because of her advocacy, Blue Shield has agreed to cover them.

16. Ms. Blackstock asserted that Claimant's physicians who treat his PANDAS are specialists, and none of them accept Medi-Cal. She explained that in order for Medi-Cal to cover the IVIG treatment, the prescription for IVIG would need to come from a physician that accepts Medi-Cal. Ms. Blackstone contended that she is unaware of any physician who treats PANDAS, prescribes IVIG, and accepts Medi-Cal.

17. Claimant's mother stated that she purchased the Blue Shield PPO coverage in March 2018, and changed from Medi-Cal managed care to Medi-Cal Fee-for-Service coverage, all upon the advice of a SGPRC Insurance Specialist. She chronicled the hospitalizations set forth in Factual Finding 6A, the great difficulty Claimant and his family have had obtaining assistance when Claimant is in crisis and engaging in violent and aggressive behavior, and she described being dismissed by healthcare professionals after spending 40 hours in the emergency room, being mistreated by law enforcement, and Claimant being misdiagnosed on several

occasions. She explained that Claimant would not be able to see the specialists needed to treat his conditions without the Blue Shield insurance, and that out of Claimant's 11 physicians, only one, Dr. Yacoob, accepts Medi-Cal. Claimant's mother contended that Claimant's family cannot afford to continue to pay the Blue Shield insurance premiums. She further contended that if Claimant loses the Blue Shield insurance coverage, Claimant would not receive the IVIG treatments and his behavior and aggression will significantly worsen, and he would be at risk to himself and others.

LEGAL CONCLUSIONS

Jurisdiction and Burden of Proof

1. The Lanterman Developmental Disabilities Services Act (Lanterman Act) governs this case. (Welf. & Inst. Code, § 4500 et seq.)⁴
2. An administrative hearing to determine the rights and obligations of the parties, if any, is available under the Lanterman Act to appeal a contrary regional center decision. (§§ 4700-4716.) Claimant requested a hearing and therefore jurisdiction for this appeal was established. (Factual Findings 1-4.)
3. The standard of proof in this case is the preponderance of the evidence, because no law or statute (including the Lanterman Act) requires otherwise. (Evid. Code, § 115.)
4. When one seeks government benefits or services, the burden of proof is on him. (See, e.g., *Lindsay v. San Diego Retirement Bd.* (1964) 231 Cal.App.2d 156, 161

⁴ All undesignated statutory references are to the Welfare and Institutions Code.

(disability benefits.) In this case, Claimant requests funding for a service the service agency has not before agreed to provide and therefore he has the burden of proving by a preponderance of the evidence that he is entitled to that funding.

5. Under the Lanterman Act, the State of California accepts responsibility for persons with developmental disabilities. The Lanterman Act mandates that an "array of services and supports should be established . . . to meet the needs and choices of each person with developmental disabilities . . . and to support their integration into the mainstream life of the community." (§ 4501.) The provision of these services and supports are to be coordinated by the state's regional centers. (§ 4620, subd. (a).)

6. The California Legislature enacted the Lanterman Act "to prevent or minimize the institutionalization of developmentally disabled persons and their dislocation from family and community . . . and to enable them to approximate the pattern of everyday living of nondisabled persons of the same age and to lead more independent and productive lives in the community." (*Association for Retarded Citizens v. Department of Developmental Services* (1985) 38 Cal.3d 384, 388.)

7. Regional centers must develop and implement IPPs, which shall identify services and supports "on the basis of the needs and preferences of the consumer, or where appropriate, the consumer's family, and shall include consideration of . . . the cost-effectiveness of each option" (§ 4512, subd. (b); see also §§ 4646, 4646.5, 4647, and 4648.) The Lanterman Act assigns a priority to services that will maximize the consumer's participation in the community. (§§ 4646.5, subd. (a)(2), and 4648, subd. (a)(1), (2).)

8. Regional centers have a duty to identify and pursue all possible sources of funding for consumers receiving regional centers, including governmental or other

entities or programs required to provide or pay for a service, Medi-Cal and private insurance. (§ 4659, subd. (a)(1) and (a)(2).) They are prohibited from purchasing any service that would otherwise be available from Medi-Cal, private insurance, or a health care services plan when a consumer or a family meets the criteria of this coverage but chooses not to pursue that coverage. (§ 4659, subd. (c).) In addition, a regional center is prohibited from purchasing medical services for a consumer "unless the regional center is provided with documentation of a Medi-Cal, private insurance, or a health care service plan denial, and the regional center determines that an appeal by the consumer or family of the denial does not have merit." (§ 4659, subd. (d)(1).) However, a regional center may pay for medical or dental services while generic coverage is being pursued, but before a denial is made. (§ 4659, subd. (d)(1)(A).) The regional center may also pay for medical or dental services until the commencement of services by Medi-Cal, private insurance, or a health care service plan. (§ 4659, subd. (d)(1)(C).) SGPRC's Purchase of Service policy is consistent with the foregoing statutes in that SGPRC is prohibited from purchasing services where the service is otherwise available through a governmental agency or program, Medi-Cal, private insurance, or a health care service plan. (Ex. 7.)

9. Section 4646.4, subdivision (a)(4), requires regional centers to consider a family's responsibility for providing "similar services and supports for a minor child without disabilities"

10. Section 4648, subdivision (a)(8), prohibits regional centers from supplanting the budget of any other agency which may provide the funding in question.

Analysis

11. It is undisputed that Claimant's IVIG treatments, which have been covered by Blue Shield, have been deemed effective by his treating pediatrician in ameliorating Claimant's violent and aggressive behaviors. Claimant's IPP provides that Claimant will maintain good health, and that Claimant's parents and Soul Sherpa will advocate for IVIG treatments. SGPRC's contention that reimbursement of the Blue Shield premiums would be a duplication of services is unpersuasive. SGPRC is currently reimbursing Claimant's parents \$800 per month for Soul Sherpa to advocate for Blue Shield coverage of the \$10,000 IVIG treatments. Here, Claimant seeks reimbursement of the premium to maintain the Blue Shield insurance, which is not the same and therefore not duplicative. Similarly, the Service Agency's contention that Claimant has access to a generic resource is without merit. The uncontradicted testimony of Ms. Blackstock and Claimant's mother established that there are no physicians in the Medi-Cal network that treat PANDAS and prescribe IVIG. Accordingly, there is no generic resource available to Claimant for coverage of the IVIG treatment. SGPRC must reimburse Claimant's monthly Blue Shield premium to ensure that Claimant meets the goals stated in his IPP.

12. In this case, Claimant is utilizing both private insurance and a public/generic resource, Medi-Cal, to obtain medical services. He established by a preponderance of the evidence that no generic resource is available to access the service/treatment, specifically IVIG, that he needs to meet Outcome #2 as outlined in his IPP. Claimant further established by a preponderance of the evidence that while the IVIG treatment is covered by his private insurance, his family cannot afford the monthly premiums. SGPRC reimbursement of the monthly premium is not duplicative of the reimbursement paid to Claimant's parents for services provided by Soul Sherpa.

13. Claimant requested reimbursement of Blue Shield premiums so that he could continue to receive IVIG treatments but did not provide evidence of when his treatment plan would be reviewed or when he would receive the maximum benefit of the treatments. Therefore, SGPRC shall reimburse Claimant's parents the current amount of the Blue Shield monthly premium retroactive to September 23, 2019, and review the provision of these services in six months as required by SGPRC's Purchase of Service policy.

ORDER

1. Claimant's appeal is granted. The San Gabriel/Pomona Regional Center shall reimburse Claimant's parents the amount of Claimant's Blue Shield of California monthly premium retroactive to September 23, 2019.

2. San Gabriel/Pomona Regional Center shall review Claimant's reimbursement request consistent with Legal Conclusion 13 above.

DATE:

CARMEN D. SNUGGS

Administrative Law Judge

Office of Administrative Hearings

NOTICE

This is the final administrative decision; both parties are bound by this decision. Either party may appeal this decision to a court of competent jurisdiction within 90 days.