

# RECORD IMPOUNDED

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SUPERIOR COURT OF NEW JERSEY  
APPELLATE DIVISION  
DOCKET NOS. A-2298-17T4  
A-2344-17T2

M.M. and S.O.,<sup>1</sup>

Appellants,

v.

CATASTROPHIC ILLNESS IN  
CHILDREN RELIEF FUND  
COMMISSION,

Respondent.

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A.O.,

Appellant,

v.

CATASTROPHIC ILLNESS IN  
CHILDREN RELIEF FUND  
COMMISSION,

Respondent.

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<sup>1</sup> We use initials and pseudonyms to preserve the children's privacy. The matters are sealed. R. 1:38-11(b)(2).

Submitted (A-2298-17) and Argued (A-2344-17)  
March 6, 2019 – Decided April 10, 2019

Before Judges Koblitz, Currier and Mayer.

On appeal from the New Jersey Catastrophic Illness in  
Children Relief Fund Commission.

M.M. and S.O., appellants pro se in A-2298-17.

A.O., appellant, argued the cause pro se in A-2344-17.

Gurbir S. Grewal, Attorney General, attorney for  
respondent in A-2298-17 (Melissa H. Raksa, Assistant  
Attorney General, of counsel; Marie L. Soueid, Deputy  
Attorney General, on the brief).

Marie L. Soueid, Deputy Attorney General, argued the  
cause for respondent in A-2344-17 (Gurbir S. Grewal,  
Attorney General, attorney; Melissa H. Raksa,  
Assistant Attorney General, of counsel; Marie L.  
Soueid, on the briefs).

#### PER CURIAM

We consolidate these appeals for the purpose of writing one opinion and remand for an explanation of why defendant, the Catastrophic Illness in Children Relief Fund Commission, (the Commission or CICRF), N.J.S.A. 26:2-148 to -159, reimbursed the parents for their uncovered medical expenses incurred by their children's hyperbaric oxygen therapy (HBOT) in 2015 but not in 2016.

## I. Peter

After A.O. and his wife's four-year-old son Peter was bit by a deer tick, they took him to numerous doctors, who suggested the family "wait and see" if the traditional Lyme disease symptoms manifested, but none did. His father states that a year later, Peter "developed full blown psychosis," "suffered from inappropriate laughter, motor tics, anxiety, separation anxiety, intrusive thoughts, disorientation, weight loss, low muscle tone, weakness, body pains and stiffness, poor eye contact, impulsivity, rages, loss of remorse, loss of emotional warmth, loss of ability to read and do math and decline in gross motor skills." He also lost the ability to eat, to speak, all "cogitative and academic abilities," and control of his bowel and bladder. As a result, Peter was unable to attend school. Prior to this unexplainable behavior, Peter was "fluent in two languages while in kindergarten," mathematically talented, and a very "easygoing social individual."

Every doctor who examined Peter dismissed Lyme disease as the culprit, resulting in over four years of misdiagnosis and mistreatment. In 2013, when Peter was eight years old, Dr. Charles Ray Jones diagnosed Peter with Lyme disease with infection-induced autoimmune encephalopathy and began the traditional treatment for Lyme disease with oral antibiotics and intravenous

immunoglobulin (IVIG).<sup>2</sup> His progress was "slow but steady" until he "plateau[ed]" in February 2015. Dr. Jones then prescribed HBOT, which drastically improved Peter's abilities. Dr. Jones reported that Peter "became more social, . . . talk[ed] in sentences," and was "able to play simple games with his parents." HBOT improved his focus, ended his "episodes of destructive rages," treated his anxiety, and helped him regain bowel and bladder control. Additionally, the treatment allowed Peter to attend school for two hours a day. Dr. Jones explained Peter's life depends on continued treatment with HBOT.

On December 7, 2016, the Commission reviewed this information, found A.O. eligible for reimbursement, and authorized the distribution of \$33,296.50 for Peter's uncovered medical expenses from January 1 to December 31, 2015, including HBOT treatment.

In January 2017, A.O. again sought reimbursement for approximately \$30,000 of Peter's uncovered medical bills from January 1 to December 31, 2016. Although Peter was "eligible" for reimbursement, "[t]he Commission voted to remove . . . HBOT from eligible expenses." The award was adjusted to

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<sup>2</sup> IVIG is a blood product used to treat antibody deficiencies. Clinical uses of intravenous immunoglobulin, U.S. Nat'l Library of Medicine (Apr. 14 2005), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1809480/>.

reflect this exclusion, and A.O. was awarded \$13,110.77. The Commission affirmed this decision in a December 6, 2017 letter.

## II. Susan

M.M. and S.O.'s youngest daughter, Susan, suffered severe brain injuries during her birth in 2010. Her diagnosis is hypoxic ischemic encephalopathy. Her parents describe Susan as being "a quad cerebral palsy" with "medication resistant seizures, visual impairments, respiratory insufficiencies, digestive problems, auditory impairments and many developmental delays." Susan was prescribed HBOT and stem cell treatments by Dr. Lowe and, according to her parents, has had "remarkable results." After receiving both treatments, Susan can "'army crawl,' . . . see, understand, make some meaningful sounds and only has [a] handful . . . of myoclonic seizures per month."

In 2016, the CICRF reimbursed Susan's parents approximately \$50,000 in expenses incurred in 2015 for HBOT and other treatment. In 2017, her parents applied for further unreimbursed expenses for 2016 HBOT treatment and, for the first time, stem cell treatment. Both 2016 requests were denied. Susan's parents were reimbursed only \$15,849 in connection with Susan's other medical treatment for 2016. The Commission affirmed this decision in a December 11, 2017 letter.

### III. Analysis

The scope of appellate review of an administrative decision is limited. Lewis v. Catastrophic Illness in Children Relief Fund Comm'n, 336 N.J. Super. 361, 369 (App. Div. 2001). In reviewing a final agency decision, the Appellate Division must defer to an agency's expertise and superior knowledge of its field. Dep't of Children & Families, Div. of Youth & Family Servs. v. T.B., 207 N.J. 294, 301 (2011); see also Campbell v. N.J. Racing Comm'n, 169 N.J. 579, 588 (2001) (granting deference to agency expertise on technical matters). This court "may not second-guess those judgments of an administrative agency which fall squarely within the agency's expertise." In re Stream Encroachment Permit, Permit No. 0200-04-0002.1 FHA, 402 N.J. Super. 587, 597 (App. Div. 2008).

"In order to reverse an agency's judgment, an appellate court must find the agency's decision to be 'arbitrary, capricious, or unreasonable, or . . . not supported by substantial credible evidence in the record as a whole.'" In re Stallworth, 208 N.J. 182, 194 (2011) (quoting Henry v. Rahway State Prison, 81 N.J. 571, 580 (1980)). "[A]lthough the scope of review of an agency's decision is circumscribed, an appellate court's review of an agency decision is 'not simply a pro forma exercise in which [the court] rubber stamp[s] findings that are not

reasonably supported by the evidence.'" Mejia v. N.J. Dep't of Corr., 446 N.J. Super. 369, 376-77 (App. Div. 2016) (alterations in original) (quoting In re Taylor, 158 N.J. 644, 657 (1999)).

Reasons must be set forth so that we can review whether the actions were arbitrary or capricious. In re Issuance of Permit by Dep't of Env'tl. Prot., 120 N.J. 164, 172-73 (1990); see Bailey v. Bd. of Review, 339 N.J. Super. 29, 33 (App. Div. 2001) (stating we should not defer to an administrative determination unless we have "confidence that there has been a careful consideration of the facts in issue and appropriate findings addressing the critical issues in dispute"). "[W]e insist that the agency disclose its reasons for any decision, even those based upon expertise, so that a proper, searching, and careful review by this court may be undertaken." Balagun v. N.J. Dep't of Corr., 361 N.J. Super. 199, 203 (App. Div. 2003).

In 1987, the Legislature found "children have the highest average medical costs among the population as a whole," and as a result, some families are "push[ed] . . . into bankruptcy and others towards seeking inferior medical care." N.J.S.A. 26:2-148(c), (b). In response, the Legislature enacted the Catastrophic Illness in Children Relief Fund Act (the Act), which created a non-lapsing, revolving fund earmarked "to provide assistance to children and their families

whose medical expenses [related to a catastrophic illness] extend beyond the families' available resources." N.J.S.A. 26:2-148(e); N.J.S.A. 26:2-151.

Under the Act, a "catastrophic illness" is defined as "any illness or condition the medical expenses of which are not covered by any other State or federal program or any insurance contract and exceed 10% of the first \$100,000 of annual income of a family plus 15% of the excess income over \$100,000." N.J.S.A. 26:2-149(a). "The moneys necessary to establish and meet the purposes of the [Act] are generated by a one dollar annual surcharge per employee for all employers who are subject to the New Jersey Unemployment Compensation Law." Lewis, 336 N.J. Super. at 365-66 (citing N.J.S.A. 26:2-157).

The Act statutorily creates the Commission to effectuate its purpose. N.J.S.A. 26:2-151. The Commission is composed of the Commissioner of Health, the Commissioner of Human Services, the Commissioner of Children and Families, the Commissioner of Banking and Insurance, the State Treasurer, and seven New Jersey residents, two of which must be "provider[s] of health care services to children." N.J.S.A. 26:2-151. The Commission is tasked with administering the fund by establishing procedures to apply for reimbursement,



determining eligibility, calculating the reimbursement amount, and processing the fund awards. N.J.S.A. 26:2-154(a) to (c).

A family seeking reimbursement must apply each year, listing costs already incurred from the prior twelve-month time period. N.J.A.C. 10:155-1.4; N.J.A.C. 10:155-1.5(d); N.J.A.C. 10:155-1.13; N.J.A.C. 10:155-1.12(a)(2) (mandating the Commission must meet and determine eligibility). Even after the Commission deems a recipient "eligible, . . . disbursements on behalf of a child shall be limited by the monies available," giving the Commission discretion on whether to approve the award requested. N.J.A.C. 10:155-1.3(b); N.J.A.C. 10:155-1.7 (establishing caps per child). Further, the award is subject to the rules and regulations adopted by the Commission. N.J.S.A. 26:2-154(i); N.J.S.A. 26:2-156.

N.J.A.C. 10:155-1.14 provides a non-exhaustive list of eligible health services which the Commission may fund. N.J.A.C. 10:155-1.14(a)(14) allows reimbursement for "[e]xperimental medical treatment/experimental drugs in connection with an FDA<sup>[3]</sup>-approved clinical trial, which are provided by

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<sup>3</sup> The federal Food and Drug Administration (FDA) is tasked with regulating clinical trials of drugs and medical devices "in human volunteers to see whether they should be approved for wider use in the general population." Conducting Clinical Trials, U.S. Food and Drug Administration (last updated June 15, 2016),

licensed health care providers." The regulation further notes applications for these treatments "may require additional review." N.J.A.C. 10:155-1.14(a)(14).

The FDA has not approved stem cell treatment for hypoxic ischemic encephalopathy-induced cerebral palsy. See FDA Warns About Stem Cell Therapies, U.S. Food and Drug Administration (last updated Nov. 16, 2017), <https://www.fda.gov/forconsumers/consumerupdates/ucm286155.htm>. Nor has Susan been accepted into a stem cell clinical trial. Because the current application for reimbursement for stem cell treatment is the first request and was denied pursuant to the regulations, we affirm the denial of reimbursement for out-of-pocket expenses in connection with Susan's stem cell treatment.

The children's unreimbursed HBOT treatment expenses were approved for 2015 and thus are in a different category. HBOT has not been approved by the FDA as a treatment for cerebral palsy or Lyme disease. Hyperbaric Oxygen Therapy: Don't Be Misled, U.S. Food and Drug Administration (Aug. 22, 2013), <https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm364687.htm>.

Neither Peter nor Susan's HBOT treatments were part of a clinical trial. The Commission argues it was within its wide discretion to deny 2016 HBOT costs

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<https://www.fda.gov/drugs/developmentapprovalprocess/conductingclinicaltrials/default.htm>.

because it is not on the non-exhaustive list of eligible health services in N.J.A.C. 10:155-14(a)(14). The Commission offers no explanation, however, as to why the children's HBOT treatment was covered in 2015, but not in 2016.

The essence of arbitrariness is where the same set of facts results in one decision on one occasion and a contrary decision on another occasion. Black's Law Dictionary defines "arbitrary" as "[d]epending on individual discretion; of, relating to, or involving a determination made without consideration of or regard for facts, circumstances, fixed rules, or procedures." Black's Law Dictionary (10th ed. 2014); Definition of arbitrary, Merriam-Webster (last visited Mar. 26 2019), <https://www.merriam-webster.com/dictionary/arbitrary> ("existing or coming about seemingly at random or by chance or as a capricious and unreasonable act of will"). The same regulations were in effect in 2015 and 2016. Why unreimbursed HBOT expenses were covered for these two families in 2015 and not in 2016 must be explained. We remand for the Commission to set forth its reasons for the change in reimbursement. We affirm the denial of reimbursement for Susan's stem cell therapy.

Affirmed in part and reversed and remanded in part. We do not retain jurisdiction.

I hereby certify that the foregoing  
is a true copy of the original on  
file in my office.



CLERK OF THE APPELLATE DIVISION