

# CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND

Annual Report to the Governor  
and Legislature of the State of New Jersey,  
in accordance with N.J.S.A. 26:2-159 (2019)

Phil Murphy, Governor

Sheila Oliver, Lieutenant Governor

Janice Prontnicki, Chairperson,  
Catastrophic Illness in Children Relief Fund Commission

Christian Heiss, Executive Director

*State Fiscal  
Year 2019:  
July 2018  
through  
June 2019*

# CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION



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The Honorable Phil Murphy  
Governor of the State of New Jersey  
State House  
Trenton, New Jersey 08625

Dear Governor Murphy,

I am pleased to present you with the Catastrophic Illness in Children Relief Fund Annual Report to the Governor and Legislature of the State of New Jersey, State Fiscal Year 2019.

From July 2018 through June 2019, the Commission approved \$7.8 million in grant awards on 410 applications to 357 New Jersey families for children's medical expenses not covered by other payment sources. Since December 1989, the Commission has awarded approximately \$270 million to over 9,200 families.

The Catastrophic Illness in Children Relief Fund provides meaningful relief for New Jersey families struggling to cope with the financial consequences of a child's medical condition or episode. It is one of the most impactful programs that the State of New Jersey offers, and I thank you for your efforts to spread the message that New Jersey families do not have to bear the high cost of their children's care alone.

Janice Prontnicki, M.D., M.P.H., F.A.A.P.  
Commission Chairperson  
Catastrophic Illness in Children Relief Fund

## EXECUTIVE SUMMARY

The Catastrophic Illness in Children Relief Fund (CICRF, or the Fund) provides financial assistance to families whose children have experienced an illness or condition not fully covered by insurance, any other state or federal program, or any other resource. The Fund provides grants to pay for expenses that exceed 10% of the first \$100,000 of a family's income plus 15% of income over \$100,000.

**In State Fiscal Year 2019, the Commission that oversees the Fund approved \$7.8 million in grant awards on 410 applications to 357 New Jersey families.** Other key statistics:

- The average award per application was \$19,032. Awards ranged from \$917 to \$100,000.<sup>1</sup>
- The average annual income of families submitting applications to the Fund was \$66,168. Incomes ranged from \$0 to \$758,178, with a median income of \$43,454.
- The average verified eligible medical expense per application was \$27,557. Eligible medical expenses ranged from \$254 to \$338,305.

**Since the first awards were approved in December 1989, the Fund has awarded \$270 million to over 9,200 New Jersey families.** The Fund provides financial relief for expenses associated with a wide range of medical diagnoses, from simple bone fractures to rare genetic disorders.

Any family, regardless of income or health coverage status, may be just one illness or accident away from expenses that can have potentially devastating financial consequences. To ensure all New Jersey families are aware of the Fund, the Commission and the State Office conduct many outreach and education activities in conjunction with county Special Child Health Case Management units and other stakeholders. In State Fiscal Year 2019, this included attendance at conferences for the New Jersey Chapter of the American Academy of Pediatrics, Autism NJ, the New Jersey League of Municipalities, and the National Association of Social Workers.

The commissioners and State Office staff of the Catastrophic Illness in Children Relief Fund are committed to the Fund's mission: making a difference in the lives of children and their parents faced with extraordinary medical expenses. The commissioners and staff work hard every day to ensure the Fund continues to serve as a critical financial safety net for New Jersey families.

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<sup>1</sup> Fund disbursements per child are capped at \$100,000 per year (N.J.A.C. 10:155-1.7(a)).

**ACKNOWLEDGEMENTS**

The Catastrophic Illness in Children Relief Fund Commission thanks the New Jersey Department of Human Services for administrative support underpinning the operations of the Fund, and the Office of the Attorney General for legal advice and counsel. The Commission also acknowledges the contributions of ex officio designees, including:

- Steve Shultz, Department of Human Services
- Dawn Mergen, Department of Health
- Anthony Valenzuela, Department of the Treasury
- Ellen DeRosa, Department of Banking and Insurance (Commission Vice-Chairperson)

This report was prepared by the State Office of the Catastrophic Illness in Children Relief Fund.

## BACKGROUND

The Catastrophic Illness in Children Relief Fund was established to provide financial assistance to families whose children have experienced an illness or condition not fully covered by insurance, state or federal program, or any other resource. The Fund is designed to provide a financial safety net for families struggling with a child's previously-incurred medical expenses.

The statute authorizing the Fund may be found at N.J.S.A. 26-2:148 *et seq.*; regulations governing Fund operations are codified at N.J.A.C. 10:155.

## Eligibility

A child 21 years of age and under who is a resident of New Jersey is eligible to apply to the Fund through his or her parent or legal guardian.

The Fund Commission may award funds to a family whose child has a "catastrophic illness," defined at N.J.S.A. 26:2-149 as eligible medical expenses exceeding 10% of the first \$100,000 of annual income of a family plus 15% of income over \$100,000. Income and expenses are measured in any consecutive 12-month time period prior to the application; applications may be submitted for 12-month periods starting as early as January 1988. All expenses are subject to program regulations which include caps for certain types of expenses, with an overall cap of \$100,000 per child, per year.

## Financing

The Fund is a non-lapsing, revolving trust fund, invested and reinvested by the Department of the Treasury and administered by the Commission. Income to the Fund is derived from a \$1.50 per employee annual surcharge for all employers subject to the New Jersey "Unemployment Compensation Law." The Fund contracts with the Department of Labor and Workforce Development to collect the surcharge; interest earned on Fund balances is reinvested in the Fund.

## Commission

The Catastrophic Illness in Children Relief Fund is governed by a 12-member Commission. Members include seven public members appointed to 5-year terms by the Governor (with the advice and consent of the Senate), and the Commissioners of the State Departments of Health, Human Services, Children and Families, Banking and Insurance, and the State Treasurer, who serve *ex officio*.

The Commission is responsible for developing policies and procedures for operation of the Fund, and meeting regularly to review and make eligibility decisions on applications to the Fund for financial assistance. In accordance with P.L. 2007 c. 342, the Commission was established in the Executive Branch and allocated within the Department of Human Services, but is "independent of any supervision or control by the department or by any board or officer thereof."

## State Office of the Fund

The State Office of the Fund is responsible for administering the Fund on a day-to-day basis on behalf of the Commission, including:

- Screening applications for eligibility;
- Determining the reasonableness of provider and vendor charges;
- Preparing applications for review and consideration by the Commission;
- Overseeing payments to providers, vendors, and in some cases families; and
- Negotiating or settling the recovery of funds if a family recovers damages or a financial award from another source for the child's medical expenses.

The State Office is overseen by an Executive Director, who serves at the pleasure of the Commission. The Executive Director serves as Secretary and Treasurer of the Commission, and is an ex officio, non-voting member of all Commission committees.

## Special Child Health and Early Intervention Services

The Fund was established in conjunction with the Special Child Health Services program, which is administered by the Department of Health as Special Child Health and Early Intervention Services (SCHEIS). SCHEIS works with the Fund to ensure families are aware of and connected to other sources of health care financing in New Jersey by making referrals and helping with the application process for other programs and benefits like NJ FamilyCare (Medicaid) or Charity Care.

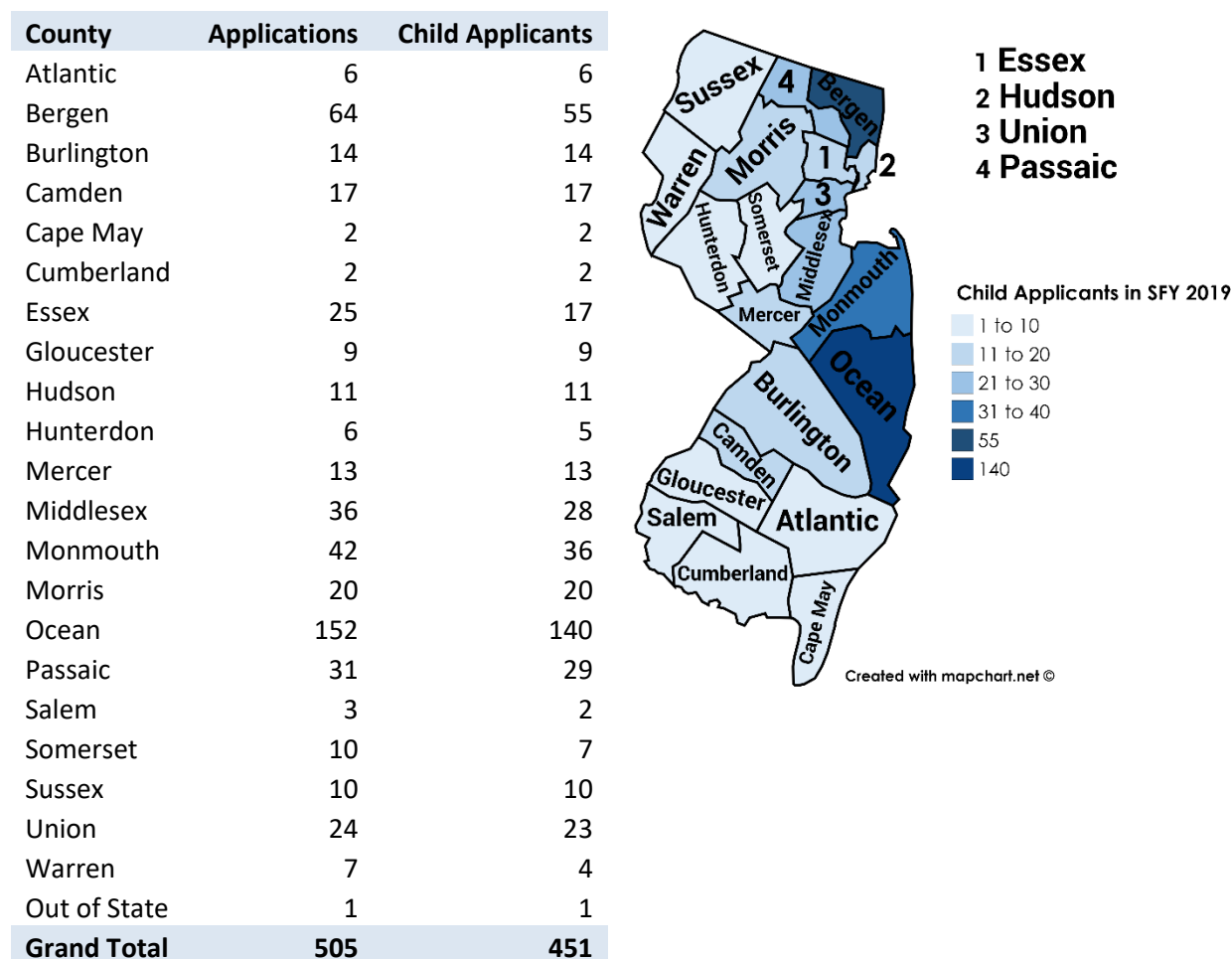
Additionally, the Fund contracts with SCHEIS through a Memorandum of Agreement to provide education and support to the public and applicants on program eligibility and the application process, conduct cross-referrals between SCHEIS programs and the Fund, and provide the Fund with information about an applicant child's medical history and access to services.

## SERVICE STATISTICS

### Number of Program Participants

In State Fiscal Year 2019, the State Office received 505 new applications on behalf of 451 children from 21 counties, including one application from outside New Jersey. Families may apply for multiple 12-month periods in a single fiscal year.

**Figure 1: Applicants to Catastrophic Illness in Children Relief Fund, State Fiscal Year 2019**



The State Office processed 664 applications in State Fiscal Year 2019. The Commission approved payments on 410 applications to 357 families, including 26 reconsiderations and 5 appeals. 33 families had applications for more than one 12-month period approved in the fiscal year.

## Medical Diagnoses

The Fund continues to see a wide range of diagnoses underlying the significant medical expenses families submit for considerations. In State Fiscal Year 2019, the diagnosis categories with 10 or more applications were:

Medical Diagnosis Category	Number of Applications
Visual Disorders	83
Cerebral Palsy	80
Epilepsy and Recurrent Seizures; Convulsions	75
Autism Spectrum Disorder	55
Obsessive-Compulsive, Anxiety, and Phobic Disorders	52
Lack of Coordination	39
Teeth, Jaw, and Oral Soft Tissue Disorders	38
Muscle Weakness, Spasm, or Unspecified Disorder	37
Encephalopathy; Other Brain Disorder	30
Attention Deficit and/or Hyperactivity Disorder	29
Delays in Language Development	29
Heart Disease or Defect	26
Ear and Hearing Disorders	25
Symbolic Dysfunction	24
Delay in Development	23
Gastro-Esophageal Reflux Disease; Other Esophageal Disease	23
Lack of Expected Development	23
Asthma	20
Chromosomal Abnormalities	19
Other Congenital Malformations of Brain	19
Scoliosis	18
Hydrocephalus; Other Cerebral Degeneration	17
Microcephaly	16
Conduct Disorders	15
Muscular Dystrophies And Other Myopathies	15
Major Depressive Disorder	14
Spinal Muscular Atrophy	13
Congenital Anomalies of Musculoskeletal System	10
Dysphagia	10
Failure to Thrive	10
Paralysis	10
Psychological Development Disorder	10
Spina Bifida	10

See Appendix C for a list of diagnosis categories with 4 or more applications in the fiscal year, including associated ICD-9 and ICD-10 diagnosis codes.

## Expenditures per Participant

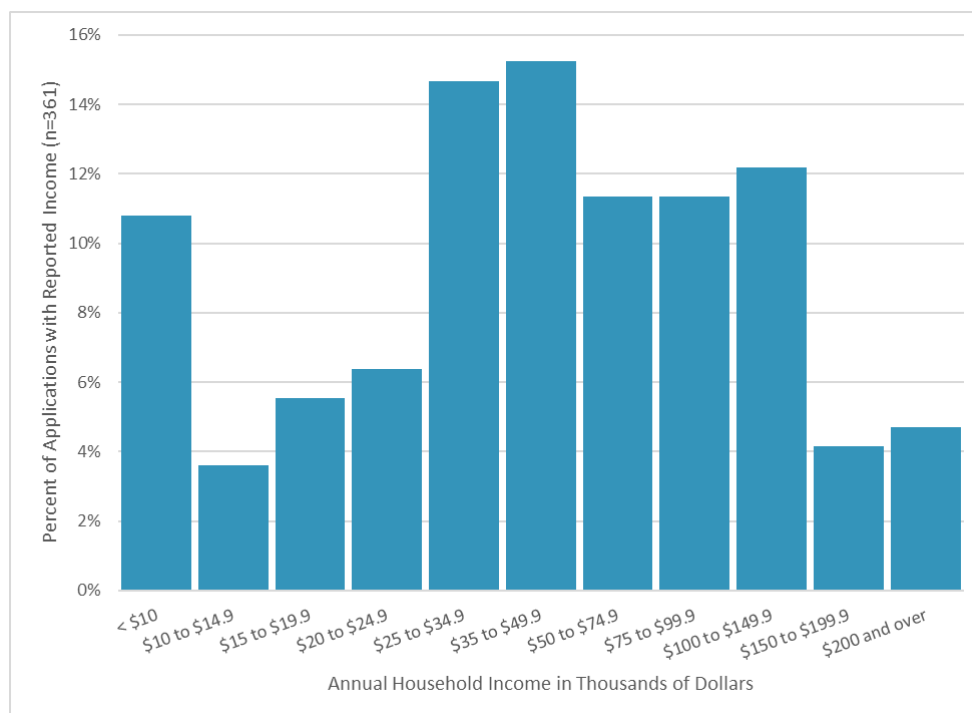
The Commission approved awards totaling \$7,803,312 after application of caps and negotiated discounts. The average payment per award was \$19,032; payments ranged from \$917 to \$100,000.

	Eligible	Reconsidered	Appealed	Ineligible	Grand Total
Applications Processed	379	27	17	241	664
Payable Applications	379	26	5	0	410
Total Approved Awards	\$8,587,623	\$210,230	\$76,415	-	\$8,874,268
Total Paid After Caps and Discounts	\$7,532,152	\$210,230	\$60,930	-	\$7,803,312
Minimum Payment	\$917	\$4,112	\$2,362	-	\$917
Maximum Payment	\$90,419	\$100,000	\$8,171	-	\$100,000
Average Payment	\$19,874	\$8,086	\$12,186	-	\$19,032

## Income and Expenditures of Participant Families

The average, verified household gross income of all families that submitted applications in the fiscal year, whether deemed eligible for reimbursement or not, was \$66,168. Incomes ranged from \$0 to \$758,178 with a median income of \$43,454.

Figure 2: Annual Household Incomes of Fund Applicants, State Fiscal Year 2019



Of the 361 applications with verified incomes, the average income of the 262 applications submitted and determined eligible for payment in State Fiscal Year 2019 was \$69,762, with a range of \$0 to \$758,178 and a median of \$45,889.

When determining eligibility, the State Office of the Fund reviews medical expenses for reasonableness of provider and vendor charges, and will negotiate with providers to lower the cost of medical care charged to applicant families. Payments are subject to an annual cap per family of \$100,000 as well as caps on payments for some categories of services. In cases of special hardship, payments on behalf of applicants may exceed \$100,000.

In State Fiscal Year 2019 the State Office verified eligible medical expenses that ranged from \$254 to \$338,305; the average verified eligible medical expense was \$27,557. Applicant families submitted a total of \$11,656,743 in eligible expenses to the Fund.

Of the 505 applications submitted to the Fund, 5 reported that the child was uninsured (1.0%).

### Eligible Health Services

The Fund considers a broad range of health services that may not always be reimbursable under traditional health insurance policies. Additionally, the Fund is unique in that it considers non-traditional health expenses such as home modifications and the purchase of specialized, modified vehicles to accommodate a child's disability and modifications to subsequent vehicles purchased by a family. The Fund does not reimburse for elective cosmetic surgery or special education services required as a result of a medical condition.

N.J.A.C. 10:155 identifies the categories of health services that are considered to be eligible and for which a family may submit for review to the Commission. The following summarizes the percentage of total award amount for each category of eligible health services in applications approved by the Commission in State Fiscal Year 2019:

Category of Health Service	Percent	Category of Health Service	Percent
Ancillary Services <sup>2</sup>	0.5	Hospital – Specialty Out-of-State	3.8
Disposable Medical Supplies	0.5	Long Term Care <sup>3</sup>	1.7
Durable Medical Equipment	2.5	Pharmacy	1.2
Funeral Expenses	0.0	Physician Services	13.2
Home Health Care	0.7	Specialty Pediatric Ambulatory <sup>4</sup>	13.4
Home Modification	9.6	Temporary Shelter	0.4
Hospital - In State	2.6	Transportation <sup>5</sup>	2.2
Hospital - Out of State	0.9	Vehicle Modification	32.1
Hospital - Specialty In-State	0.3	Vehicle Purchase	14.5

<sup>2</sup> Ancillary Services: CT Scans, Infusion Therapy, Laboratory, MRI, X-Ray, and Other.

<sup>3</sup> Long Term Care: Primarily behavioral health residential treatment, including substance use and eating disorders.

<sup>4</sup> Specialty Pediatric Ambulatory: Acupuncture, Applied Behavior Analysis, Aqua Therapy, Audiology, Chiropractic, Dental Care, Hippotherapy, Massage Therapy, Music Therapy, Nutritional Counseling, Occupational Therapy, Outpatient Psychotherapy and Counseling (Clinical Social Worker/ Psychologist), Physical Therapy, Psychotherapy (Licensed Physician/ Psychiatrist), Speech Therapy, Swallowing Therapy, and Other.

<sup>5</sup> Transportation: Ambulance, Mileage, Parking, and Other.

## FUND AND STATE OFFICE MANAGEMENT

### Staffing

Christian Heiss was appointed Executive Director of the State Office effective April 27, 2019. In addition, in State Fiscal Year 2019 the Fund employed 11 full-time professional staff, including (1) fiscal manager, (1) accounting assistant, (1) executive assistant, (1) secretarial assistant, and (7) analysts.

### Legislative and Regulatory Changes

There were no amendments to the Commission's enabling legislation during the fiscal year. No changes were made to the Commission's regulations during the fiscal year, but the Commission did vote to propose a number of changes which are not yet finalized. These are discussed below, under Policy Issues).

### Fiscal Operations

Once approved by the Commission, fiscal staff of the State Office process payments to providers, vendors, and other parties on behalf of applicant families. Due to systems to ensure proper payment, including use of the New Jersey Comprehensive Finance System, some payments approved by the Commission in one fiscal year may not be processed until the following fiscal year.

Payments for awards and State Office operating expenses are processed from the Fund. The Fund cannot have a negative balance. The following table outlines the revenues and expenditures from the Fund in State Fiscal Years 2017 through 2019:

	STATE FISCAL YEAR '17	STATE FISCAL YEAR '18	STATE FISCAL YEAR '19
Initial Fund Balance (July 1)	\$ 3,592,436	\$ 4,905,234	\$ 2,883,127
<i>Revenues</i>			
Services and Assessments	\$ 9,218,332	\$ 9,984,360	\$ 9,420,394
Investment Earnings	\$ 15,952	\$ 69,829	\$ 90,136
<b>Total Revenue</b>	\$ 9,234,284	\$ 10,054,189	\$ 9,510,530
<b>Total Available Funds</b>	\$ 12,826,720	\$ 14,959,423	\$ 12,393,657

	STATE FISCAL YEAR '17	STATE FISCAL YEAR '18	STATE FISCAL YEAR '19
<i>Expenditures</i>			
Fund Awards	\$ 6,380,879	\$ 10,337,513	\$ 8,185,805
Operating Expenses	\$ 1,540,607	\$ 1,738,783 <sup>6</sup>	\$ 1,581,068
<b>Total Expenditures</b>	<b>\$ 7,921,486</b>	<b>\$ 12,076,296<sup>6</sup></b>	<b>\$ 9,766,873</b>
Final Fund Balance (June 30)	\$ 4,905,234	\$ 2,883,127	\$ 2,626,784

## Policy Issues

In State Fiscal Year 2019 the Fund paid \$1,096,657 towards vehicle purchase and \$2,486,377 in vehicle modifications. The \$3,583,034 total vehicle and modifications payments represented 46% of payments disbursed in FY '19; in FY '18 these categories totaled 51% of payments, while they averaged 33% of payments in the previous 5 years, State Fiscal Year '13 through '17.

In State Fiscal Year 2005, when vehicle and modification payments represented 49% of total Fund awards, the Commission adopted amendments to the regulations to limit the vehicle and modification proportion of payments by reducing the lifetime cap for vehicle purchases in N.J.A.C. 10:155-1.7 from \$25,000 per applicant to \$15,000. The desired effect was observed: vehicle purchase and modification payments trended downward to 20% of total Fund awards in 2013, as the percent of families served with this category of awards decreased from 29% of families in 2005 to 9% of families in 2013.

However, since 2013 there has been an average 4.3% per year increase in payments for this category, and 19% of families served by the Fund in 2019 received awards associated with vehicle purchase or modification. To address the continued rise in vehicle purchase and modification costs, the Commission voted on February 13, 2019 to revise N.J.A.C. 10:155-1.7 to further reduce the lifetime vehicle purchase cap to \$7,500 per applicant.

The Commission noted a concern with physical therapy and occupational therapy costs in State Fiscal Year 2019. The Commission reviewed applications in the fiscal year with \$1,592,306 in total physical, occupational, and speech therapy costs submitted, for which the Commission approved \$642,110 after applying the \$3,000 annual cap on speech, language and hearing services (N.J.A.C. 10:155-1.7(d)) and reasonable rates to all services. Without reasonable rates and caps, the nearly \$1.6 million in therapy costs would have represented 20% of expenses approved by the Commission. To further control costs in these categories, the Commission also voted on February 13, 2019 to codify the use of reasonable rates within Fund regulations using the Centers for Medicare and Medicaid

<sup>6</sup> Note: Operating expenses accrued prior to July 1, 2018 totaled \$1,647,895. In October 2018, \$90,888 in expenditures for retroactive pay increases approved through union negotiations for State Office staff was applied to the end-of-year Fund balance, resulting in total expenditures of \$12,076,296 in State Fiscal Year 2018.

Services (CMS) rates, and to establish uniform annual caps for physical, occupational, and speech therapies at \$5,000 per therapy per year.

Finally, the Commission voted on February 13, 2019 to propose to amend the rule governing the child's residency for eligibility purposes to more closely align with the statute, N.J.S.A. 26:2-155. Rather than requiring that the child's residency be tied to a parent's, this proposed change would require that the child's own residency be taken into consideration.

As of the date of this report, all proposed regulatory changes were under review.

On May 24, 2019, the Food and Drug Administration approved the first gene therapy, trade name Zolgensma, for children under 2 diagnosed with spinal muscular atrophy, a rare childhood disease that causes progressive loss of muscular function. Novartis has set the price of Zolgensma at \$2.1 million or \$425,000 a year spread out over five years. Although one of the rarest childhood diseases, representing only 1 in 6 to 10 thousand births, spinal muscular atrophy was one of the top 15 diagnoses for applicants to the Fund in State Fiscal Year 2019. The Commission and State Office intend to closely monitor applications for the impact this gene therapy may have on the Fund in future fiscal years.

## Public Information

In recent years, State Office public information efforts have included statewide paid advertising, as well as community outreach and public relations efforts designed to improve knowledge of the Fund among New Jersey families. In order to better guide outreach efforts, in State Fiscal Year 2019 the State Office began analyzing the number of child applicants received from each of the 21 counties in New Jersey compared to the population of children under age 18 in each county, a proxy for the population served by the Fund.

**Table 1: Average Annual Applicants to Fund by County, State Fiscal Years 2014-2019**

County	Average Annual Applicants to Fund	Average Population Under 18	Expected Annual Applicants to Fund if Proportional to Population	Average Annual Difference, Actual Applicants minus Expected Applicants
Atlantic	9	58,682	16.6	-7.6
Bergen	54.6	199,751	56.5	-1.9
Burlington	20.8	95,615	27.1	-6.3
Camden	19.2	117,091	33.1	-13.9
Cape May	3	16,733	4.7	-1.7
Cumberland	2.8	36,592	10.4	-7.6
Essex	31	189,303	53.6	-22.6
Gloucester	14.8	65,498	18.5	-3.7
Hudson	17.2	137,252	38.9	-21.7
Hunterdon	5.6	25,571	7.2	-1.6
Mercer	16.4	79,442	22.5	-6.1
Middlesex	34.6	181,534	51.4	-16.8
Monmouth	31.2	136,375	38.6	-7.4
Morris	33	108,019	30.6	2.4
Ocean	165	139,865	39.6	125.4
Passaic	37.2	121,284	34.3	2.9
Salem	2.4	13,919	3.9	-1.5
Somerset	13.2	75,155	21.3	-8.1
Sussex	13.2	29,690	8.4	4.8
Union	25.4	130,364	36.9	-11.5
Warren	7.6	22,027	6.2	1.4
<b>Grand Total</b>	<b>560.4</b>	<b>1,979,761</b>	<b>560.4</b>	

In State Fiscal Year 2014 through 2019, the State Office received an average of 560.4 applications per year, or approximately one applicant for every 3,500 children under the age of 18 in the state. However, applications from Ocean County skew the results, as there was one applicant per 848 children in that county, compared to one applicant per 4,653 children in the rest of the state combined. If the figures for Ocean County are removed the calculation of expected annual

applicants, the resulting list gives a more accurate picture of counties that have fewer applicants to the Fund than would be expected, and therefore should be targeted for outreach activities.

**Table 2: Average Annual Applicants to Fund by County, State Fiscal Years 2014-2019, Ocean County excluded**

County	Average Annual Applicants to Fund	Average Population Under 18	Expected Annual Applicants to Fund if Proportional to Population	Average Annual Difference, Actual Applicants minus Expected Applicants
Atlantic	9	58,682	12.6	-3.6
Bergen	54.6	199,751	42.9	11.7
Burlington	20.8	95,615	20.5	0.3
Camden	19.2	117,091	25.2	-6.0
Cape May	3	16,733	3.6	-0.6
Cumberland	2.8	36,592	7.9	-5.1
Essex	31	189,303	40.7	-9.7
Gloucester	14.8	65,498	14.1	0.7
Hudson	17.2	137,252	29.5	-12.3
Hunterdon	5.6	25,571	5.5	0.1
Mercer	16.4	79,442	17.1	-0.7
Middlesex	34.6	181,534	39.0	-4.4
Monmouth	31.2	136,375	29.3	1.9
Morris	33	108,019	23.2	9.8
Passaic	37.2	121,284	26.1	11.1
Salem	2.4	13,919	3.0	-0.6
Somerset	13.2	75,155	16.2	-3.0
Sussex	13.2	29,690	6.4	6.8
Union	25.4	130,364	28.0	-2.6
Warren	7.6	22,027	4.7	2.9
<b>Grand Total<sup>7</sup></b>	<b>395.4</b>	<b>1,839,896</b>	<b>395.4</b>	

Based on this analysis, the State Office intends to focus outreach efforts in State Fiscal Year 2020 in the following counties (in order from most underserved by the Fund to least underserved): Hudson, Essex, Camden, Cumberland, Middlesex, Atlantic, Somerset and Union. Outreach in these 8 counties would result in more than 46 additional applicants to the Fund per year if the applicants to the Fund were proportional to the child population. The State Office intends to conduct analysis in the first months of State Fiscal Year 2020 to identify organizations to partner with in these counties for outreach purposes, including hospitals, federally qualified health centers, and schools for students with disabilities.

<sup>7</sup> Grand Total excluding 165 applications from Ocean County

In addition to targeted outreach, The Fund continued to present to groups not familiar with the Fund or to those who are in contact with families, including community organizations, schools, individual families and small groups representing parents of children with disabilities.

The Fund attended and/or exhibited at several conferences and fairs, including the American Academy of Pediatrics School Health Conference, and annual conferences of Autism NJ, the NJ League of Municipalities, and the National Association of Social Workers. Additional outreach efforts included program information mailings to Family Advisory Committee members, county Special Child Health Case Management units, parents of ill children identified through our newspaper clipping service and to reporters who have written stories on ill children.

### **First Lady and DHS Commissioner Attend Holiday Event**

On December 18, 2018, New Jersey First Lady Tammy Murphy joined Department of Human Services Commissioner Carole Johnson, State Office staff, and members of the CICRF Commission to welcome families that have received grants from the Fund and to highlight the program for other New Jersey Families.

“No one should face insurmountable expenses due to their child’s complex illness or medical condition,” First Lady Murphy said. “New Jersey has a fund to ensure that families have access to financial assistance to alleviate the burden during these challenging times. We encourage families to reach out and apply for these grants.”

“A family’s financial means should not be a barrier to necessary medical care for their very sick children,” said Commissioner Johnson. “New Jersey offers a special fund to help families meet costs that are not covered by health insurance so that children can get the care they need.”

## CONCLUSION

Any family in New Jersey may find needed financial assistance from the Catastrophic Illness in Children Relief Fund if their child's uncovered medical expenses are disproportionate to their income. Since the Fund is intended to be a resource for all New Jersey families facing potentially catastrophic medical bills, every effort must be made to ensure every corner of the state is aware of the program. Targeting outreach activities to a variety of audiences involved with children's issues and diversifying advertising efforts may help spread the message more efficiently and cost effectively.

There continues to be a pressing need for the Fund, regardless of insurance status, employment, or eligibility for other State and federal programs. The Fund strives to fill the gaps in service that have caused hardship for many New Jersey families.



## APPENDIX A: MEDICAL DIAGNOSIS CATEGORIES

There were 1426 individual diagnoses submitted for the 415 children with applications that included diagnosis data reviewed by the Catastrophic Illness in Children Relief Fund Commission in State Fiscal Year 2019. There was an average of 3.4 diagnoses per child; the greatest number of diagnoses submitted for one child was 20.

Diagnoses were categorized under 743 ICD-9 or ICD-10 codes, either from data submitted by the applicant's family or via categorization by State Office staff from written diagnosis descriptions. The largest single code was F84.0, Autistic disorder.

In order to gain a better understanding of the diagnoses submitted to the Fund, the State Office grouped similar diagnoses by both type of diagnosis and ICD-9/ ICD-10 code. The following table shows code groupings that resulted in 4 or more instances of a diagnosis group. Together these represent 1044 (73 percent) of the 1426 individual diagnoses submitted.

Medical Diagnosis Category	ICD-9 and ICD-10 Codes	Count
Visual Disorders	362.2-379.x, H18.613-H55.x, Q13.4 <sup>8</sup>	83
Cerebral Palsy	333.71, 343.x, G80.x	80
Epilepsy and Recurrent Seizures; Convulsions	345.x, 780.3, G40.x, R56.x	75
Autism Spectrum Disorder	299.x, F84.0, F84.8, F84.9	55
Obsessive-Compulsive, Anxiety, Phobic Disorders	300.x, F40.x, F41.x, F42.x	52
Lack of Coordination	315.4, 781.3, R26.89, R27.x	39
Teeth, Jaw, and Oral Soft Tissue Disorders	520-528.9, K02.x-K14.8, M26.x <sup>9</sup>	38
Muscle Weakness, Spasm, or Unspecified Disorder	728.x, M62.x	37
Encephalopathy; Other Brain Disorder	348.x, 768.7, 779.7, G92, G93.x, P91.x	30
Attention Deficit and/or Hyperactivity Disorder	314.x, F90.x, R41.840	29
Delays in Language Development	315.31, 315.32, F80.x	29
Heart Disease or Defect	414.9-430, 745.5-747.1, Q20.4-Q25.x <sup>10</sup>	26
Ear and Hearing Disorders	381.x-389.x, H66.93-H91.x <sup>11</sup>	25
Symbolic Dysfunction	784.x, R48.x	24
Delay in Development	315.x, F82	23
Gastro-Esophageal Reflux Disease; Other Esophageal Disease	530.x, K21.x	23
Lack of Expected Development	783.x, R62.x	23
Asthma	493.x, J45.x	20

<sup>8</sup> Visual Disorders codes include: 362.2, 365.9, 366, 367, 368.01, 369.x, 370.9, 371, 376.3, 377.x, 377.75, 378.x, 379.x, H18.613, H27.1, H40.009, H47.x, H50.x, H51.11, H52.x, H53.x, H54.x, H55.x, and Q13.4.

<sup>9</sup> Teeth, Jaw and Oral Soft Tissue Disorders include: 520, 521.x, 522.8, 524.x, 525.9, 528.9, K02.x, K12.2, K14.8, and M26.x

<sup>10</sup> Heart Disease or Defect includes: 414.9, 416, 428, 430, 745.5, 746.89, 747.1, Q20.4, Q21.x, Q22.1, Q23.x, Q24.9, and Q25.x

<sup>11</sup> Ear and Hearing Disorders include: 381.x, 382, #85.33, #89.x, H66.93, H69.83, H81.49, H90.x, H91.x

Medical Diagnosis Category	ICD-9 and ICD-10 Codes	Count
Chromosomal Abnormalities	758.x, Q90.x-Q99.x <sup>12</sup>	19
Other Congenital Malformations of Brain	742.x, Q04.x	19
Scoliosis	737.x, M41.x	18
Hydrocephalus; Other Cerebral Degeneration	330.8, 331.x, G91.x	17
Microcephaly	742.1, Q02	16
Conduct Disorders	312.34, 313.81, F63.x, F91.x	15
Muscular Dystrophies And Other Myopathies	359.x, G71.x	15
Major Depressive Disorder	296.32, F32.x, F33.x	14
Spinal Muscular Atrophy	335.1, G12.x	13
Congenital Anomalies of Musculoskeletal System	756.x, Q87.0	10
Dysphagia	787.x, R13.x	10
Failure to Thrive	779.34, 783.41, P92.6, R62.51	10
Paralysis	334.1, 342.91, 344.1, G81, G82.x	10
Psychological Development Disorder	F88, F89	10
Spina Bifida	741.x, Q05.x	10
Mood Disorders	296.x, F34.x, F39	9
Myoneural Disorders	336.8, 337.9, 358.x, G70.89	8
Post-Traumatic Stress Disorders	309.x, F43.x	8
Congenital Hypotonia	P94.2	7
Drug and Alcohol Abuse	F10.2, F11.x, F12.20, F14.10	7
Eating Disorders	307.1, F50.x	7
Malignant Neoplasm	191.x, C49.9, C64, C71.6, C72.9	7
Sleep Apnea	327.x, 780.53, G47.x	7
Arnold-Chiari Syndrome	Q07.x	6
Cleft Palate	749.21, Q35.9, Q37.x	6
Leukemia	204, C91.x, C92.1	6
Nutritional Deficiency	269.x, E53.8, E55.9, E63.9	6
Sepsis	A41.x, B37.7	6
Thyroid Disorder	244.x, 246.8, E03.x, E07.9	6
Chronic Respiratory Failure	770.7, J96.x	5
Diabetes	250.x, E13, E23.2	5
Specific Personality Disorders	301.83, F60.x	5
Central Auditory Processing Disorder	H93.25	4
Feeding Difficulties	R63.3	4
Intellectual Disabilities	F79	4
Lyme Disease and Related Conditions	88.81, A69.x	4

<sup>12</sup> Chromosomal Abnormalities include: 758.x, Q90.x, Q91.3, Q93.x, Q96.9, Q99.x

**APPENDIX B: AUTHORIZING LEGISLATION**

Catastrophic Illness in Children Relief Fund

N.J.S.A. 26:2-148 et seq.

NEW JERSEY GENERAL AND PERMANENT STATUTES

(UPDATED THROUGH P.L. 2019, ch. 84 and J.R.4)

Available at <https://www.njleg.state.nj.us/>

**26:2-148. Findings, declarations**

The Legislature finds and declares that:

a. Although the majority of Americans are covered by some form of health insurance, families nevertheless lack protection against the high cost of chronic or single episodes of serious illness that may destroy their resources. An illness resulting in this potentially devastating financial consequence is referred to as a catastrophic illness.

b. Catastrophic illnesses often threaten to push some families into bankruptcy and others toward seeking inferior medical care and present a major problem for this nation's health care system in that catastrophic illnesses account for over 20% of this nation's health expenditures.

c. The impact of catastrophic illnesses on the family is especially acute in that children have the highest average medical costs among the population as a whole.

d. It is the public policy of this State that each child of this State should have access to quality health care and adequate protection against the extraordinarily high costs of health care services which are determined to be catastrophic and severely impact upon a child and his family.

e. To this end, it is incumbent upon the State to provide assistance to children and their families whose medical expenses extend beyond the families' available resources.

L. 1987,c.370, s.1.

**26:2-149 Definitions relative to catastrophic illness in children.**

2. As used in this act:

- a. "Catastrophic illness" means 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.
- b. "Child" means a person 21 years of age and under.
- c. "Commission" means the Catastrophic Illness in Children Relief Fund Commission.
- d. "Family" means a child and the child's parent, parents or legal guardian, as the case may be, who is legally responsible for the child's medical expenses.
- e. "Fund" means the Catastrophic Illness in Children Relief Fund.
- f. "Income" means all income, from whatever source derived, actually received by a family.
- g. "Resident" means a person legally domiciled within the State for a period of three months immediately preceding the date of application for inclusion in the program. Mere seasonal or temporary residence within the State, of whatever duration, does not constitute domicile. Absence from this State for a period of 12 months or more is prima facie evidence of abandonment of domicile. The burden of establishing legal domicile within the State is upon the parent or legal guardian of a child.

L.1987,c.370,s.2; amended 1993, c.103, s.1; 1998, c.143, s.1; 2003, c.260, s.1.

**26:2-150. Catastrophic Illness in Children Relief Fund**

The "Catastrophic Illness in Children Relief Fund" is established as a nonlapsing, revolving fund. The fund shall be administered by the commission, and shall be credited with monies received pursuant to section 10 of this act.

The State Treasurer is the custodian of the fund and all disbursements from the fund shall be made by the treasurer upon vouchers signed by the chairman of the commission. The monies in the fund shall be invested and reinvested by the Director of the Division of Investment in the Department of the Treasury as are other trust funds in the custody of the State Treasurer in the manner provided by law. Interest received on the monies in the fund shall be credited to the fund.

L. 1987,c.370, s.3.

**26:2-151 Catastrophic Illness in Children Relief Fund Commission.**

4. There is established in the Executive Branch of the State government, the Catastrophic Illness in Children Relief Fund Commission. For the purposes of complying with the provisions of Article V, section IV, paragraph 1 of the New Jersey Constitution, the commission is allocated within the Department of Human Services, but notwithstanding that allocation, the commission shall be independent of any supervision or control by the department or by any board or officer thereof.

The commission shall consist of the Commissioner of Health, the Commissioner of Human Services, the Commissioner of Children and Families, the Commissioner of Banking and Insurance, and the State Treasurer, who shall be members ex officio, and seven public members who are residents of this State, appointed by the Governor with the advice and consent of the Senate for terms of five years, two of whom are appointed upon the recommendation of the President of the Senate, one of whom is a provider of health care services to children in this State and two of whom are appointed upon the recommendation of the Speaker of the General Assembly, one of whom is a provider of health care services to children in this State. The five public members first appointed by the Governor shall serve for terms of one, two, three, four and five years, respectively.

Each member shall hold office for the term of his appointment and until his successor has been appointed and qualified. A member of the commission is eligible for reappointment.

Each ex officio member of the commission may designate an officer or employee of the ex officio member's department to represent the member at meetings of the commission, and each designee may lawfully vote and otherwise act on behalf of the member for whom he constitutes the designee. Any designation shall be in writing delivered to the commission and filed with the office of the Secretary of State and shall continue in effect until revoked or amended in the same manner as provided for designation.

L.1987, c.370, s.4; amended 1993, c.103, s.2; 1994, c.149, s.1; 1998, c.143, s.2; 2006, c.47, s.105; 2007, c.342, s.1; 2012, c.17, s.121.

**26:2-152. Suspension; oaths; vacancies**

Each member of the commission may be removed from office by the Governor, for cause, after a public hearing and may be suspended by the Governor pending the completion of the hearing. Each member of the commission before entering upon his duties shall take and subscribe an oath to perform the duties of his office faithfully, impartially and justly to the best of his ability. A record of the oaths shall be filed in the office of the Secretary of State.

Any vacancies in the membership of the commission occurring other than by the expiration of a term shall be filled in the same manner as the original appointment, but for the unexpired term only.

L. 1987,c.370, s.5.

**26:2-153. Officers; quorum**

6. The members shall elect a chairperson and chief executive officer of the commission who shall be one of the public members of the commission. The commission shall by rule determine the term of office of the chairperson and chief executive officer. The members shall elect a secretary and a treasurer who need not be members of the commission and the same person may be elected to serve both as secretary and treasurer.

The powers of the commission are vested in the members thereof in office from time to time and six members of the commission shall constitute a quorum at any meeting thereof. Action may be taken and motions and resolutions adopted by the commission at any meeting thereof by the affirmative vote of at least six members of the commission. A vacancy in the membership of the commission shall not impair the right of a quorum to exercise all the powers and perform all the duties of the commission.

The members of the commission shall serve without compensation, but the commission shall reimburse its members for the reasonable expenses incurred in the performance of their duties based upon the monies available in the fund.

The commission shall be appointed within three months after the effective date of this act and shall organize as soon as may be practicable after the appointment of its members.

L.1987,c.370,s.6; amended L.1994,c.149,s.2.

**26:2-154 Powers; duties.**

7. The commission has, but is not limited to, the following powers and duties:
- a. Establish in conjunction with the Special Child Health Services program established pursuant to P.L.1948, c.444 (C.26:1A-2 et seq.) a program for the purposes of this act, administer the fund and authorize the payment or reimbursement of the medical expenses of children with catastrophic illnesses;
  - b. Establish procedures for application to the program, determining the eligibility for the payment or reimbursement of medical expenses for each child, and processing fund awards and appeals. The commission shall also establish procedures to provide that, in the case of an illness or condition for which the family, after receiving assistance pursuant to this act, recovers damages for the child's medical expenses pursuant to a settlement or judgment in a legal action, the family shall reimburse the fund for the amount of assistance received, or that portion thereof covered by the amount of the damages less the expense of recovery;
  - c. Establish the amount of reimbursement for the medical expenses of each child using a sliding fee scale based on a family's ability to pay for medical expenses which takes into account family size, family income and assets and family medical expenses and adjust the financial eligibility criteria established pursuant to subsection a. of section 2 of this act based upon the moneys available in the fund;
  - d. Disseminate information on the fund and the program to the public;
  - e. Adopt bylaws for the regulation of its affairs and the conduct of its business, adopt an official seal and alter the same at pleasure, maintain an office at the place within the State as it may designate, and sue and be sued in its own name;
  - f. Appoint, retain or employ staff, experts or consultants on a contract basis or otherwise, who are deemed necessary, and employ investigators or other professionally qualified personnel who may be in the noncompetitive division of the career service of the Civil Service, and as may be within the limits of funds appropriated or otherwise made available to it for its purposes;
  - g. Maintain confidential records on each child who applies for assistance under the fund;
  - h. Do all other acts and things necessary or convenient to carry out the purposes of this act; and
  - i. Adopt rules and regulations in accordance with the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) necessary to effectuate the purposes of this act.
- L.1987,c.370,s.7; amended 1998, c.143, s.3, 2003, c.260, s.2.

**26:2-154.1. Settlement of claims; disposition of recovered moneys**

3. The commission is authorized to negotiate or settle a claim that the fund maintains for reimbursement against a family who has received assistance for the medical expenses of a child with a catastrophic illness pursuant to P.L.1987, c.370 (C.26:2-148 et seq.) and has recovered damages in a legal action for the child's medical expenses. Money recovered pursuant to this section shall be deposited in the fund.

L.1993,c.103.s.3.

**26:2-155 Eligibility.**

8. a. A child who is a resident of this State is eligible, through his parent or legal guardian, to apply to the program established pursuant to subsection a. of section 7 of P.L.1987, c.370 (C.26:2-154).

b. In the event a family has more than one child with a catastrophic illness, as defined pursuant to section 2 of P.L.1987, c.370 (C.26:2-149), the commission shall waive the family responsibility, as established by regulation, for the other child if the family has met the family responsibility for the first child in a State fiscal year.

L.1987, c.370, s.8; amended 1998, c.143, s.4; 2010, c.84.

**26:2-156 Financial assistance.**

9. Whenever a child has a catastrophic illness and is eligible for the program, the child, through his parent or legal guardian, shall receive financial assistance from monies in the fund subject to the rules and regulations established by the commission and the availability of monies in the fund. The financial assistance shall include, but is not limited to, payments or reimbursements for the cost of medical treatment, hospital care, drugs, nursing care and physician services.

L.1987,c.370,s.9; amended 1998, c.143, s.5, 2003, c.260, s.3.

**26:2-157 Annual surcharge per employee under unemployment compensation fund for relief fund.**

10. For the purpose of providing the moneys necessary to establish and meet the purposes of the fund, the commission shall establish a \$1.50 annual surcharge per employee for all employers who are subject to the New Jersey "Unemployment Compensation Law," R.S. 43:21-1 et seq. The surcharge shall be collected by the controller for the New Jersey Unemployment Compensation Fund and paid over to the State Treasurer for deposit in the fund annually as provided by the commission.

L.1987, c.370, s.10; amended 2007, c.342, s.2.

**26:2-158 Rules, regulations**

The State Treasurer shall adopt rules and regulations in accordance with the "Administrative Procedure Act," P.L.1968, c. 410 (C. 52:14B-1 et seq.) establishing procedures for the collection of the surcharge.

L. 1987,c.370, s.11.

**26:2-159 Annual reports.**

12. The commission shall report annually to the Governor and to each Senate and General Assembly committee with responsibility for issues affecting children, health and human services on the status of the program. The report shall include information about the number of participants in the program, average expenditures per participant, the nature and type of catastrophic illnesses for which the fund provided financial assistance, and the average income and expenditures of families who received financial assistance under the program. The commission also may make recommendations for changes in the law and regulations governing the fund.

L.1987,c.370,s.12; amended 1998, c.143, s.6.

## APPENDIX C: ADMINISTRATIVE CODE

### Catastrophic Illness in Children Relief Fund

#### Administrative Code

#### N.J.A.C 10:155

This file includes all Regulations adopted and published through the New Jersey Register, Vol. 51 No. 10, May 20, 2019

#### § 10:155-1.1 Purpose and scope

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- (a) The purpose of this subchapter is to implement the provisions of P.L. 1987, c. 370 and to:
1. Establish criteria for eligibility;
  2. Establish a standard methodology for determining the amount of financial assistance to be allocated for services of a child's health providers and vendors for families in the State of New Jersey whose child experiences uncovered medical expenses for services required to treat or manage a catastrophic illness; and
  3. Specify the procedures that shall be followed by the Catastrophic Illness in Children Relief Fund Commission.

#### § 10:155-1.2 Definitions

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The following words and terms, as used in this subchapter, shall have the following meanings, unless the context clearly indicates otherwise.

"Act" means P.L. 1987, Chapter 370, codified at N.J.S.A. 26:2-148 et seq., which establishes the Catastrophic Illness in Children Relief Fund.

"Batch" means a grouping of applications for the purpose of applying the provisions of [N.J.A.C. 10:155-1.6](#), [1.7](#) and [1.8](#).

"Catastrophic Fund" or "Fund" means the Catastrophic Illness in Children Relief Fund.

"Catastrophic illness" means any illness or condition for which the incurred medical expenses are not covered by any other source, including, but not limited to, other State or Federal agency programs, insurance contracts, trusts, proceeds from fundraising, or settlements relative to the medical condition of a child that is equal to 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000.

"Chairperson" means the chief executive officer of the Commission who is elected by the Commission membership from the public members for a term of one year.

"Child" means a person 21 years of age and under.

"Commission" means the 12 member Catastrophic Illness in Children Relief Fund Commission created by the Act and appointed by the Governor to administer the Fund. The Commission, chaired by a public member, is in the Executive Branch of the State government. For purposes of complying with the provisions of Article V, section IV, paragraph 1 of the New Jersey Constitution, the Commission is allocated within the Department of Human Services, but notwithstanding that allocation, the Commission shall be independent of any supervision or control by the Department of Human Services or by any board or officer thereof.

"Days" means calendar days.

"Eligibility standard" means that dollar amount equal to 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000.

"Executive director" means the professional employed by the Commission, in accordance with New Jersey Civil Service Commission procedures, to administer the Fund on a day-to-day basis on behalf of the Commission.

"Family" means a child and the child's parent, parents, or legal guardian, as the case may be, who is legally responsible for the child's medical expenses.

"Family responsibility" means the amount equal to 10 percent of the eligibility standard.

"Health coverage premium" means a premium for contracts, excluding automobile insurance contracts, whereby an insurer is obligated to pay or allow a benefit for the child who is covered under the policy or contract, due to bodily injury, disablement, sickness or because of any expense relating thereto or because of expense incurred in the prevention of sickness to include limited scope plans, such as hospital, medical and prescription.

"Income" means the following:

1. Wages before deductions;
2. Public Assistance;
3. Social Security Benefits;
4. Supplemental Security Income;
5. Unemployment and Workers' Compensation;
6. Strike Benefits from Union Funds;

7. Veteran's Benefits;
8. Training Stipends;
9. Alimony;
10. Child Support;
11. Military Family Allotment;
12. Regular Support from Absent Family Member;
13. Pension Payments;
14. Insurance or Annuity Payments;
15. Income from Estates and Trusts;
16. Dividends;
17. Interest Income;
18. Rental Income;
19. Royalties; and
20. Other sources of income not mentioned above. However, income does not include the following money receipts: withdrawals from a bank; sale of property, house or car; tax refunds; gifts; one-time insurance payments; or compensation from injury, unless the injury directly relates to a child's condition, which is the basis for an application being made to the Fund. Also disregarded is non-cash income and any money raised by fundraising.

"Local agency" means the Special Child Health Services Office responsible for assisting families in the application process, forwarding applications to the State Office, and making appropriate referrals to other State programs and benefits.

"State Office of Catastrophic Illness in Children Relief Fund" or "State Office" means the Office of the Executive Director of the Fund, which has responsibility for administering the Fund on a day-to-day basis on behalf of the Commission.

### § 10:155-1.3 General requirements

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(a) Pursuant to the Act, the Fund will provide assistance to families having a child with a catastrophic illness. A child shall have passed the initial screen for eligibility for the Fund's assistance when a child's incurred and verified medical expenses, as specified in this chapter for a prior consecutive 12-month period, exceed the amount equal to 10 percent of the first \$ 100,000 of verified annual income of a family plus 15 percent of the excess income over \$ 100,000.

1. Ten percent shall be the screen used for families whose income is \$ 100,000 or less.
2. Ten percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000 shall be the screen used for families whose income is more than \$ 100,000.

(b) Though the child shall be referred to as being eligible at the point in the application process when the child has passed the initial screen, actual Fund disbursements on behalf of a child shall be limited by the monies available in the Fund and shall be guided by the policies and procedures outlined in the subchapter.

(c) To be eligible for assistance, a child must be a resident of the State of New Jersey. Resident means a person legally domiciled in New Jersey for a period of three months immediately preceding the date of application for assistance to the Fund.

1. A child's state of residence is that of the parent(s) or legal guardian.
2. Establishing proof of legal domicile within New Jersey is a responsibility of the parent or legal guardian of a child.
3. Absence from New Jersey for a period of 12 months or more is prima facie evidence of abandonment of domicile.
4. Seasonal or temporary residence within the State, of whatever duration, does not constitute domicile.

### § 10:155-1.4 Initial application process

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Applications may be submitted on a year-round basis to the local agency. The name, address, and phone number for the local agencies shall be available from the State Office. The local agency shall forward written applications on forms provided by the State Office. Applications also may be submitted online through the State website: [www.njcatastrophicfund.org](http://www.njcatastrophicfund.org).

**§ 10:155-1.5 State Office and Commission review process**

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- (a) Upon receipt of the paper application from the local agency, or the web application from the family, the State Office shall consider the providers' and vendors' charges submitted.
- (b) Providers shall demonstrate licensure or certification by appropriate State or Federal agencies, if requested by the State Office.
- (c) Prior to the Commission's batched review of applications, the State Office shall prepare a disbursement schedule for each application in accordance with [N.J.A.C. 10:155-1.6](#), [1.7](#) and [1.8](#).
- (d) In a cycle of batch reviews, the Commission shall review the applications and the State Office's disbursement schedule for each application based on the annual cap and the sliding payment schedule. A decision on the Fund's level of assistance for each case will be determined. The calendar for the batch reviews shall be made available to the public by the State Office, as required by the Open Public Meetings Act.

**§ 10:155-1.6 Eligibility standard**

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Incurred, out-of-pocket medical expenses greater than 10 percent of the first \$ 100,000 of annual income for a family plus 15 percent of the excess income over \$ 100,000 threshold shall be required for eligibility consideration. Those expenses above the family responsibility and up to the cap shall be considered for reimbursement after the eligibility standard is determined and met (see examples in Appendix I).

**§ 10:155-1.7 Limits on Fund disbursements**

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- (a) The amount of Fund's disbursements on behalf of a child shall be capped at \$ 100,000 per year.
- (b) A one-time vehicle allowance will be capped at \$ 15,000 for the purchase or lease of a specialized vehicle. The allowance does not include modifications, which can be considered separately. The one-time vehicle allowance of \$ 15,000 shall be included in the total disbursement cap, in the year the vehicle allowance was disbursed.
- (c) The amount of the home modification allowance shall be capped at \$ 25,000 per year.
- (d) The amount of the speech, language and hearing services allowance shall be capped at \$ 3,000 per year.
- (e) The amount of the applied behavioral analysis services shall be capped at \$ 6,000 per year.

**§ 10:155-1.8 Sliding payment schedule**

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If adequate funds do not exist in the Fund at the point in time when a particular batch is being considered by the Commission to pay all applicants the amount of their expenses below the annual cap, a sliding payment schedule shall be used in an effort to distribute the available monies to applicants in an equitable way that considers a family's income, assets and other factors which impact the ability to pay for care.

**§ 10:155-1.9 Allocation distribution plan**

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Because the Fund's actual level of assistance to families, as determined by the Commission, shall in most, if not all, cases be less than the child's medical expenses, the Commission shall determine how the Fund's available monies shall be distributed among eligible providers and vendors. Input from the family shall be sought in the analysis preceding this determination, with guidance from the State Office.

**§ 10:155-1.10 Local agency responsibilities**

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The local agency shall make referrals and assist in the application process for other programs and benefits (for example, Medicaid, Hospital Charity Care, and other programs), where applicable.

**§ 10:155-1.11 State Office responsibilities**

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(a) The State Office shall:

1. Screen applications to determine whether a child's eligible medical expenses meet the eligibility standard.
2. Maintain oversight to the local agency responsible for assisting families with Program, accepting applications and providing local outreach/information;
3. Administer the Fund on a day-to-day basis on behalf of the Commission;
4. Monitor providers eligibility (that is, certification or other credentials);
5. Determine the reasonableness of providers and vendor charges;
6. Prepare application for review and consideration of the Commission;
7. Oversee payments to providers, vendors, and, in some cases, families; and
8. Negotiate or settle the recovery of funds disbursed in accordance with the provisions of this chapter.

**§ 10:155-1.12 Commission responsibilities**

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(a) The Catastrophic Illness in Children Relief Fund Commission shall be responsible to:

1. Develop policies and procedures for operation of the Fund; and
2. Meet to review and make decision on applications of families for financial assistance in regularly scheduled cycles.

**§ 10:155-1.13 Time period for measuring expenses and income**

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In screening a child/family for eligibility for the Fund, expenses and income shall be measured by any prior consecutive 12-month time period. The income will be reported for the same prior consecutive 12-month time period back to January 1988. Applications may be accepted any time throughout the year.

**§ 10:155-1.14 Eligible health services**

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(a) Categories of incurred expenses, which are related to the medical care of a child with an illness or condition eligible for consideration in assessing whether a family has reached its eligibility standard include, but are not limited to, the following:

1. Physician-authorized ancillaries (labs, x-rays);
2. Specialized pediatric ambulatory care, including physician-authorized rehabilitative therapies (for example, speech, occupational, and physical), physician-authorized care for treatment of substance use disorders and behavioral health care, dental care, eye care, and chiropractic care;
3. Care in an acute hospital in New Jersey (treatment for acute and chronic conditions and treatment of substance use disorders and behavioral health conditions);
4. Care in acute hospitals in other states (treatment for acute and chronic conditions and treatment of behavioral health conditions, including substance use disorders);
5. Physicians and nursing services, including immunization services, in all settings;
6. Care in specialty hospitals (for example, rehabilitative, psychiatric);
7. Long term care (respite care, hospice care, residential care, or other care);
8. Home health care (physician-authorized home health aide, physician-authorized public health nurse, physician-authorized private duty nurse or other care);
9. Pharmaceuticals (physician-authorized Federal Drug Administration approved over-the-counter and prescription drugs related to the medical condition and physician-authorized Federal Drug Administration approved medical formulas);
10. Disposable medical supplies (physician-authorized over-the-counter and prescribed supplies);
11. Durable medical equipment (for example, physician-authorized ventilators, prostheses);
12. Home modification that is related to the medical condition of the child at the time the expenses were incurred;
13. Purchase of a specialized, modified vehicle and any subsequent modifications that are related to the medical condition of the child at the time the expenses were incurred;
14. Experimental medical treatment/experimental drugs in connection with an FDA-approved clinical trial, which are provided by licensed health care providers. Applications involving experimental treatment/experimental drugs may require additional review;
15. Reasonable funeral expenses, including professional services, arrangement and supervision, facility charges, transportation (hearse and one family car), casket costs and vault or cremation urn.

Excluded items include, but are not limited to, flowers, prayer cards, books, headstones, name plates and soloist/organist; and

**16.** Family transportation and travel-related expenses including, but not limited to, mileage allowance, tolls, parking receipts, and temporary shelter costs related to the medical condition.

**(b)** Fifty percent of a health coverage premium, including supplemental and dependent coverage that is paid by a family, not to exceed 50 percent of total eligible expenses, when accompanied by eligible expenses in (a) above shall be counted toward calculating eligibility, but shall not be considered an eligible expense for reimbursement from the Fund.

#### **§ 10:155-1.15 Ineligible health services**

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**(a)** Categories of health and health-related expenses that are not eligible for consideration shall include, but are not limited to, the following:

1. Special education required as result of medical condition;
2. Elective cosmetic surgery/treatment; and
3. Modifications to vacation and secondary homes.

#### **§ 10:155-1.16 Administration of payments**

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**(a)** The State Office shall oversee processing of payments from the Fund. Though in general payments shall be made directly to providers and vendors, consideration shall be given to making payments directly to families.

**(b)** Items in [N.J.A.C. 10:155-1.14](#), Eligible health services, shall be considered for payments.

**(c)** For the purpose of providing the moneys necessary to establish and meet the purposes of the Fund, the Commission shall establish a \$ 1.50 annual surcharge per employee for all employers who are subject to the New Jersey "Unemployment Compensation Law," N.J.S.A. 43:21-1 et seq. The surcharge shall be collected by the Controller for the New Jersey Unemployment Compensation Fund and paid over to the State Treasurer for deposit in the Fund annually as provided by the statute.

**§ 10:155-1.17 Appeal process**

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(a) The following applies to the appeals:

1. Upon receipt of a determination by the State Office, an applicant who disputes that determination may appeal to the Catastrophic Illness in Children Relief Fund Commission by filing a written appeal to:

New Jersey State Department of Human Services  
Catastrophic Illness in Children Relief Fund Commission  
PO Box 0728  
Trenton, NJ 08625-0728  
Attn: Chairperson

2. Appeals must be postmarked and mailed to the above address no later than 30 days from the date of notice of the determination made by the State Office. The Commission may waive the deadline for cause.

3. The written appeal shall include all reasons and grounds for disputing the determination made by the State Office and all proof and documentation in support of the appeal.

4. The Commission shall conduct such review and analysis as is necessary to reach a decision on the appeal. At its discretion, the Commission may direct a conference to be convened with the applicant, or may refer the matter to the Office of Administrative law pursuant to the Administrative Procedure Act, N.J.S.A. 52:14B-1 et seq., and the Uniform Administrative Procedure Rules, [N.J.A.C. 1:1](#).

5. Except for appeals referred to the Office of Administrative Law, the Commission shall render a decision on the appeal within 180 days from the date of original receipt of the appeal. Appeals referred to the Office of Administrative Law shall be decided by the Commission within 45 days from the date of filing of the Initial Decision of the Administrative Law Judge, or at such later date as permitted by law.

6. A decision made by the Commission shall be final. It may be appealed to the Superior Court of New Jersey as permitted by court rules.

(b) Unless otherwise specifically ordered by the Commission, an applicant may not receive benefits from the Catastrophic Illness in Children Relief Fund while an appeal is pending at any level.

### § 10:155-1.18 Special cases

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(a) Special cases shall be referred to the Commission for its review and consideration. Special cases shall include, but are not limited to, the following:

1. In special cases in which a family has more than one child with a catastrophic illness (as defined by expenses in excess of the 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000 threshold for each child), consideration shall be given to waiving the family responsibility as outlined in [N.J.A.C. 10:155-1.2](#) for the other child/children given that the family would have already met the family responsibility for the first child in a State fiscal year.

2. For special hardship cases that come before the Commission during a batch cycle, after the standard disbursement guidelines have been applied to each case in the batch and sufficient monies remain in the Fund, consideration shall be given to waiving the standard disbursement guidelines (that is, the family responsibility and the caps as outlined in [N.J.A.C. 10:155-1.2](#) and [1.7](#)).

### § 10:155-1.19 Confidentiality of information

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Information received pursuant to the duties required by the Act shall not be disclosed publicly in such a manner as to identify individuals unless special circumstances require such disclosure and the proper notice is served and parent or legal guardian's consent is given, as may be necessary for pending legal proceedings.

### § 10:155-1.20 Recovery of Commission expenses

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(a) If a family receives assistance from the Fund for a child, in accordance with this chapter, and subsequently recovers damages or a financial award for the child's medical expenses, pursuant to a settlement or judgment in a legal action, the family shall reimburse the Fund for either:

1. The amount of assistance received from the Fund; or

2. The portion of assistance received for the injury, illness or condition covered by the damage or judgment, less the family's expenses of recovery.

(b) The Commission may negotiate or settle the recovery of such claims, for cause presented by the family to the Commission.