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 (2022)

Phil Murphy, Governor Sheila Oliver, Lieutenant Governor Janice Prontnicki, Chairperson, Catastrophic Illness in Children Relief Fund Commission Christian Heiss, Executive Director State Fiscal Year 2023: July 2022 through June 2023

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 2023.

From July 2022 through June 2023, the Commission approved \$4.4 million in grant awards on behalf of 149 New Jersey children for medical expenses not covered by other payment sources. Since December 1989, the Commission has awarded over \$200 million on behalf of New Jersey children.

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. 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.

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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 their health plan, 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 2023, the Commission that oversees the Fund approved \$4.4 million in grant awards on 160 applications on behalf of 149 New Jersey children. Other key statistics:

- The average award per application was \$27,304. Awards ranged from \$200 to \$100,000.¹
- The average annual income of families submitting applications to the Fund was \$110,848. Incomes ranged from \$0 to \$430,904 with a median income of \$85,301.
- The average verified potentially eligible medical expense per application was \$36,995. Total verified medical expenses per application ranged from \$20 to \$189,180.

Since the first awards were approved in December 1989, the Fund has awarded over \$200 million across 10,199 applications on behalf of New Jersey children. 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

"We truly went through extremely difficult times in many ways. However, you have helped us immeasurably... We were able to [use] the money to continue to provide for the help [our daughter] so desperately needed... You can take pride in knowing that your wonderful relief fund has truly provided relief, healing and gratification for a family going through severe illness."

Applicant Family

activities in conjunction with county Special Child Health Case Management units and other stakeholders.

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

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.

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:

- Lisa Asare, Department of Human Services
- Jeffery Carrick, Department of Children and Families
- Dawn Mergen, Department of Health
- Anthony Valenzuela, Department of the Treasury
- Ellen DeRosa, Department of Banking and Insurance (Commission Vice-Chairperson)
- Manuel Paulino, Department of Banking and Insurance

CONGRATULATIONS

The Catastrophic Illness in Children Relief Fund Commission congratulates Vice-Chairperson Ellen DeRosa on her retirement on June 1, 2023, after over 30 years of state service. We are grateful for her decades of excellent service to New Jersey families.

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 their health plan, a 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. Current versions of the statute and regulations are included as Appendix A and B to this report.

Eligibility

A child 21 years of age and under who is a resident of New Jersey is eligible to apply to the Fund, either alone or 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 in the 7 years prior to the application.² 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 12-month period.

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

² N.J.A.C. § 10:155-1.13, "Time period for measuring expenses and income," was amended on May 2, 2022 (54 N.J.R. 780(b)) to state that "expenses and income shall be measured by any prior consecutive 12-month time period in the seven years (84 months) prior to the date the application for assistance is postmarked and mailed, faxed, or electronically delivered to the State Office."

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;
- Negotiating discounts with providers;
- 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 (SCHS). SCHS 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 SCHS 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 SCHS 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 2023, the State Office received 285 new applications on behalf of 263 children from all 21 counties, and one from out-of-state. 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 2023

		Child
County	Applications	Applicants
Atlantic	10	9
Bergen	35	33
Burlington	17	15
Camden	15	14
Cape May	1	1
Cumberland	5	5
Essex	28	26
Gloucester	14	13
Hudson	9	8
Hunterdon	8	7
Mercer	6	6
Middlesex	14	13
Monmouth	20	16
Morris	27	24
Ocean	20	18
Out of State	1	1
Passaic	16	16
Salem	2	2
Somerset	9	9
Sussex	7	7
Union	16	15
Warren	5	5
Grand Total	285	263

In State Fiscal Year 2023, application volume was low, yet stable, as compared to years 2019 and 2020 (see Figure 2 on page 4). In 2019 the Commission determined that payment for ambulatory out-of-network services was not supported by CICRF law or regulation which resulted in a significant reduction in application volume for families using CICRF for services such as physical therapy, psychotherapy, and occupational therapy. See the Public Information section for a review of application volume by county and planned outreach efforts.

While statewide application volume may be low, increases in application submissions in certain counties are a promising sign. In State Fiscal Year 2023, applications from Camden, Essex, Gloucester, and Morris counties increased by more than fifty percent. This suggests that targeted outreach efforts increased community awareness of the Fund, particularly in the southern region of the state (see page 14 for a list of organizations engaged by the State Office).

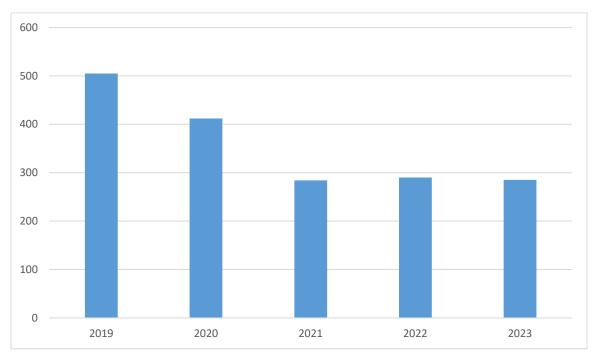


Figure 2: Applications to Catastrophic Illness in Children Relief Fund by State Fiscal Year 2019-2023

The State Office presented 258 applications to the Commission for review in State Fiscal Year 2023. The Commission approved payments on 160 applications on behalf of 149 children, including 156 eligible applications, 3 reconsiderations for applications heard as eligible prior to SFY 2023, and 1 appeal. 11 children 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 2023, the diagnosis categories with 10 or more applicants were:

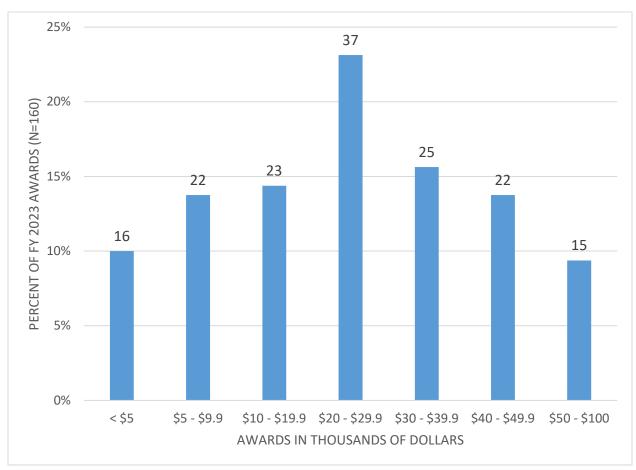
Medical Diagnosis	Number of Applicants
Cerebral Palsy	56
Epilepsy and recurrent seizures	35
Autism Spectrum Disorder	28
Lack of expected normal physiological development	27
Visual Disorders	26
Scoliosis	21
Psychological Development Disorder	19
Attention Deficit and/or Hyperactivity Disorder	16
Delays in Language Development	16
Obsessive-Compulsive, Anxiety, and Phobic Disorders	16
Chromosomal Anomalies	13
Congenital Hypotonia	13
Other disorders of brain	13
Gastro-Esophageal Reflux Disease (GERD)	12
Other disturbances of cerebral status of newborn	12
Epilepsy and Recurring Seizures; Convulsions	11
Microcephaly	10

Expenditures per Participant

The Commission approved 160 awards totaling \$4,368,569 after application of caps and negotiated discounts. The average payment per award was \$27,304; payments ranged from \$200 to \$100,000. Excluding the 3 reconsiderations for applications found eligible prior to SFY 2023, average payment per award was \$27,792; payments ranged from \$200 to \$100,000.

	Eligible	Appealed	Reconsidered, Eligible Prior to SFY 2023	Ineligible	Grand Total
Applications Processed	156	3	3	96	258
Payable Applications	156	1	3	0	160
Total Approved Awards after Caps and Discounts	\$4,356,586	\$6,716	\$5,267		\$4,368,569
Minimum Payment	\$200		\$725	-	\$200
Maximum Payment	\$100,000		\$1,550	-	\$100,000
Average Payment	\$27,691		\$1,756	-	\$27,304

Figure 3: Award Distribution, State Fiscal Year 2023



Income and Expenditures of Participant Families

Whether found eligible for reimbursement or not, the average verified household gross income of the 206 families that submitted applications in the fiscal year was \$110,848. Incomes ranged from \$0 to \$430,904 with a median income of \$85,301. The State Office was not able to verify the household income for 28 percent of applications submitted. Because the ratio of verified expenses to household income is required to determine eligibility for the Fund, these applications could not be fully processed during the fiscal year.

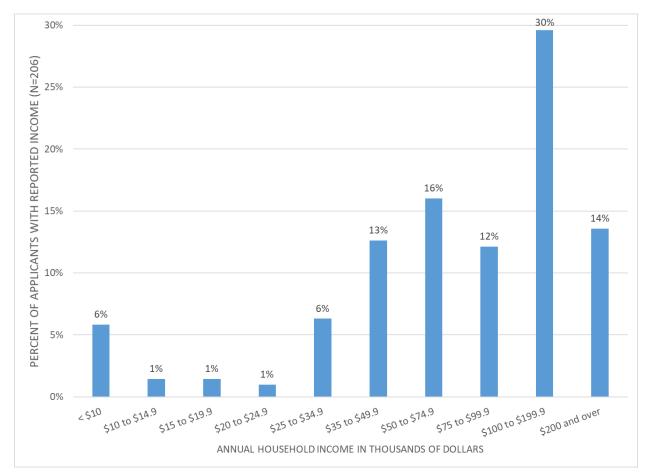


Figure 4: Annual Household Incomes of Fund Applicants, State Fiscal Year 2023

Of the 206 applications with verified incomes, the average income of the 77 applications submitted and determined eligible for payment in State Fiscal Year 2023 was \$112,867 with a range of \$10,567 to \$405,051 and a median of \$83,496.

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.³ In cases of special hardship, payments on behalf of applicants may exceed \$100,000 if funds are available.

In State Fiscal Year 2023, the State Office verified potentially eligible medical expenses that averaged \$36,995 per application; individual application expenses ranged from \$20 to \$189,180. Applicant families submitted a total of \$7,029,087 in potentially eligible expenses to the Fund.

³ Limits on Fund disbursements, listed at N.J.A.C. 10:155-1.7, include: an overall cap of \$100,000 per year; onetime vehicle purchase allowance of \$7,500; Speech, language, and hearing services capped at \$3,000 per year; and Applied Behavior Analysis (ABA) services capped at \$6,000 per year.

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 2023:

Category of Health Service	Percent	Category of Health Service	Percent
Ancillary Services ⁴	0.1	Hospital – Specialty Out-of-State	5.7
Disposable Medical Supplies	0.7	Long Term Care ⁵	2.6
Durable Medical Equipment	1.3	Pharmacy	0.5
Funeral Expenses	0.1	Physician Services	1.4
Home Health Care	0.0	Specialty Pediatric Ambulatory ⁶	3.3
Home Modification	19.7	Temporary Shelter	0.5
Hospital - In State	1.4	Transportation ⁷	2.1
Hospital - Out of State	0.2	Vehicle Modification	51.7
Hospital - Specialty In-State	0.8	Vehicle Purchase	7.7

FUND AND STATE OFFICE MANAGEMENT

Staffing

In State Fiscal Year 2023 the Fund employed 11 full-time professional staff, including (1) executive director, (1) deputy executive director, (1) fiscal manager, (1) provider relations specialist, (1) fiscal program specialist, (1) senior analyst, (3) analysts (1) executive assistant, and (1) secretarial assistant.

⁴ Ancillary Services: CT Scans, Infusion Therapy, Laboratory, MRI, X-Ray, and Other.

⁵ Long Term Care: Primarily behavioral health residential treatment, including substance use and eating disorders. ⁶ 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.

⁷ Transportation: Ambulance, Mileage, Parking, and Other.

Legislative and Regulatory Changes

There were no amendments to the Commission's enabling legislation during the fiscal year.

Final rules were published in the New Jersey Register on August 1, 2022:

- defining "special education" as written in the Individuals with Disabilities Education (IDEA) Act, 20 U.S.C. § 1401(29); and
- defining "resident" for purposes of the Fund as dependent on the child's status, not that of the parent or guardian.

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 2020 through 2023:

	STATE FISCAL YEAR '20	STATE FISCAL YEAR '21	STATE FISCAL YEAR '22	STATE FISCAL YEAR '23 ⁸
Initial Fund Balance (July 1)	\$2,626,784	\$4,580,454	\$6,943,416	\$10,562,380
Revenues Services and Assessments	\$9,310,001	\$9,177,615	\$9,023,420	\$9,465,000
Investment Earnings	\$65,137	\$4,481	\$15,882	\$430,949
Total Revenue	\$9,375,138	\$9,182,096	\$9,039,302	\$9,895,949
Total Available Funds	\$12,001,922	\$13,762,550	\$15,982,718	\$20,458,329

Revenues

⁸ Revenue figures for Fiscal Year 2023 as of September 20, 2023. Slight revisions to revenue figures may occur until the Annual Comprehensive Financial Report is finalized. Any future updates will be reflected in the next annual report.

·	STATE FISCAL YEAR '20	STATE FISCAL YEAR '21	STATE FISCAL YEAR '22	STATE FISCAL YEAR '23
Fund Awards	\$6,110,123	\$5,344,181	\$3,811,448	\$4,607,696
Operating Expenses	\$1,311,345	\$1,474,953	\$1,608,890	\$1,841,351
Total Expenditures	\$7,421,468	\$6,819,134	\$5,420,338	\$6,449,047
Final Fund Balance (June 30)	\$4,580,454	\$6,943,416	\$10,562,380	\$14,009,282

Expenditures

Policy Issues

The State Office continues to work diligently to identify policies that require updating and clarification.

The Commission has discussed the potential to eliminate "family responsibility" as defined in N.J.A.C. 10:155-1.2. "Family responsibility" in the CICRF program is the amount of incurred expenses due to a child's illness or condition, uncovered by other sources, equal to 10 percent of the CICRF income eligibility standard. Per N.J.A.C. 10:155-1.6, only expenses above family responsibility (up to any applicable caps or limits) are considered for reimbursement by the program.

Currently, family responsibility is equal to 1 percent of the first \$100,000 of a family's income in the 12-month period the uncovered expenses occurred, plus 1.5 percent of the excess income over \$100,000. This level was set by P.L. 1998, c. 143. In 1999, the average annual premium in the United States for family health care coverage was \$5,791 or 13.7 percent of the median annual income of \$42,000.

The Commission noted that health care expenses continue to rise as a proportion of total family expenses, and posed whether changing the formulas to calculate family responsibility could reduce the amount held back from reimbursements to families on behalf of their children.

The Commission asked the State Office to draft a contextual analysis and recommendations to submit for Commission consideration by the Legislative and Personnel & Finance committees.

Public Information

In State Fiscal Year 2023, State Office public information efforts expanded to include targeted community outreach and public relations strategies designed to improve knowledge of the Fund among New Jersey families.

In State Fiscal Year 2015 through 2022, the State Office received an average of 506.3 applications per year, or approximately one application for every 3,919 children under the age of 18 in the state. In State Fiscal Year 2023, the State Office received 284 applications (excluding one out-of-state application), or approximately one application for every 6,986 children under the age of 18 in the state.

County	Average Annual Applications, SFY 2015- 2022	Average Population Under 18, CY 2015-2022	Expected Annual Applications, Proportional to Population	Actual Applications, SFY 2023	Actual Applications minus Expected Applicants
Atlantic	8.3	57,274	14.6	10	-4.6
Bergen	49.9	198,921	50.8	35	-15.8
Burlington	18.3	94,474	24.1	17	-7.1
Camden	18.3	116,978	29.8	15	-14.8
Cape May	2.9	16,447	4.2	1	-3.2
Cumberland	2.5	36,507	9.3	5	-4.3
Essex	30.8	194,261	49.6	28	-21.6
Gloucester	13.5	64,760	16.5	14	-2.5
Hudson	13.8	139,746	35.7	9	-26.7
Hunterdon	6.1	24,619	6.3	8	1.7
Mercer	14.1	80,124	20.4	6	-14.4
Middlesex	33.8	182,402	46.5	14	-32.5
Monmouth	28.9	133,333	34.0	20	-14.0
Morris	30.1	105,387	26.9	27	0.1
Ocean	140.5	149,073	38.0	20	-18.0
Passaic	32.6	121,322	31.0	16	-15.0
Salem	2.5	13,814	3.5	2	-1.5
Somerset	14.1	73,359	18.7	9	-9.7
Sussex	11.9	28,309	7.2	7	-0.2
Union	25.6	131,711	33.6	16	-17.6
Warren	8.0	21,220	5.4	5	-0.4
Grand Total	506.3	1,984,041	506.3	284 ⁹	-222.3

Table 1: Applications by County, State Fiscal Year 2023 compared to 2015-2022 Average

⁹ Excludes one application received from a family that did not reside in New Jersey.

As noted on pages 3 and 4 of this report, application volume in Fiscal Year 2023 was low, representing a stable trend compared to State Fiscal Year 2020. Less than expected applications were observed in 19 of the 21 counties. Yet, the counties with the greatest negative difference between expected applications by child population (based on 2015-2022 averages) and 2023 application volume were Essex, Hudson, Middlesex, Ocean and Union (See Table 1). Targeted outreach in these 5 counties could result in more than 100 additional applications to the Fund if they reached the average application volume proportional to child population. The State Office of the Fund will continue to use the county-by-county analysis began in State Fiscal Year 2019, using application volume compared to population of children under age 18 (a proxy for the population served by the Fund) to guide outreach efforts.

Outreach Efforts

The State Office implemented regional stakeholder engagement to increase Fund awareness and referrals, and included three Parent Advisors to the Family Advisory Committee, to advise the Commission on the interests of families and to assist in its mandate to disseminate information to potential applicants.

In Fiscal Year 2023, the State Office met with or presented to a diverse group of organizations across the State, including the:

- Camden County Early Childhood Comprehensive Systems
- Camden County HUB Partners group
- Children's Hospital of Philadelphia
- Greater New York Abilities Expo
- Healthy Mothers Healthy Babies Coalition of Burlington County
- Hopewell Valley Regional School District, Counseling Department
- New Jersey Education Association Conference
- New Jersey Integrated Mental Health Conference (Monmouth)
- New Jersey State School Nurses' Association Conference
- New Jersey YMCA State Alliance
- Southern New Jersey Perinatal Cooperative
- Trenton Health Team
- Weisman Children's Hospital (southern)
- Woods Services, Inc.

CICRF was chosen by public vote as the "Innovative Funder Strategies" winner of the inaugural New Jersey Social Innovation Awards on February 23, 2023. The exposure connected the State Office with other programs interested in potential referrals to our program.

In April 2023, three Parent Advisors—Nicole Heiser, Kati Neustadter, and Erica Hines—were inducted to the Family Advisory Committee to represent the interests of families in discussions concerning Fund operations, propose recommendations to the Commission, and conduct community outreach.

On June 7, 2023, the Fund celebrated 35 years of service to New Jersey families at its Family Appreciation Day. Eleven families joined Fund staff and commissioners at the Social Profit Center at Mill One in Hamilton to highlight the financial relief the Fund provides New Jersey families, connect families with extraordinary medical expenses with each other for camaraderie and support, and recruit family volunteers to assist with promoting the Fund.

The Fund Pays Dividends

The main purpose of the Fund is to provide financial relief to families with potentially catastrophic medical bills, but the Fund also helps families in ways other than direct reimbursement. Fund analysts and SCHS case managers help families through the Fund application process, but often identify other resources and connections that can continue to help families for years to come. Fund commissioners also step in to help families with their expertise. The following vignette illustrates the Fund's work through applications heard by the Commission in State Fiscal Year 2023.

A family was being sued by their child's provider for failure to pay a \$10,375 bill for an emergency procedure. The family provided CICRF documentation which showed that the child was eligible for FamilyCare Plan A, and that Medicaid was billed but nothing was paid. The provider was not enrolled with the Medicaid program, but Medicaid staff confirmed that the child was treated in a facility that accepts Medicaid, so by law the family could not be billed for the cost of care (except for any authorized cost sharing). The New Jersey Medicaid Medical Director contacted the billing provider directly to clarify the law with them.

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 exceed 10 percent of their income.10 Since the Fund is intended to be a resource for all New Jersey families facing potentially catastrophic medical bills, every effort continues be made to ensure people throughout the state are aware of the program. Targeting outreach activities to a variety of audiences involved with children's issues, including intensive county-by-county outreach, and diversifying advertising efforts may help spread the message more efficiently and effectively.

There continues to be a pressing need for the Fund, regardless of health coverage 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.

¹⁰ Plus 15 percent of any income over \$100,000

APPENDIX A: 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. 2022, ch. 114 and J.R.6)

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 B: 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. 54 No. 20, October 17, 2022

§ 10:155-1.1 Purpose and scope

(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

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.

"Special education," shall mean as defined at 20 U.S.C. § 1401(29), specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including:

1. Instruction conducted in a classroom, in the home, in hospitals and institutions, and in other settings; and

2. Instruction in physical education.

"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

(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 state in which the child resides, either with a parent or legal guardian, or alone if the child has reached the age of 18 or is emancipated from the care and custody of a parent or guardian.

2. Establishing proof of legal domicile within New Jersey is a responsibility of the parent or legal guardian of a child, or the child, if the child has reached the age of 18, or is emancipated from the care and custody of a parent or guardian. For the definition of domicile, see N.J.A.C. 9A:5-1.1.

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

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.

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

(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

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

(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 \$ 7,500 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 \$ 7,500 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

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.

\S 10:155-1.9 Allocation distribution plan

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

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

(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

(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.

\S 10:155-1.13 Time period for measuring expenses and income

In screening a child/family for eligibility for the Fund, expenses and income shall be measured by any prior consecutive 12-month time period in the seven years (84 months) prior to the date the application for assistance is postmarked and mailed, faxed, or electronically delivered to the State Office. The income will be reported for the same prior consecutive 12-month time period. Applications may be accepted any time throughout the year.

§ 10:155-1.14 Eligible health services

(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

(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

(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

(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

(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

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

(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.