

JULY 2008 - JUNE 2009

**The Annual Report to the Governor
and the Legislature of the State of New Jersey**

On The Catastrophic Illness in Children Relief Fund (CICRF) Act



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

Chris Christie, Governor

Kim Guadagno, Lieutenant Governor
Jennifer Velez, Commissioner of Human Services

Jane Schreadley Lorber, CICRF Chairperson

Ralph J. Condo, CICRF Executive Director

CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION

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Honorable Chris Christie
Governor
State of New Jersey
State House
Trenton, New Jersey 08625

Dear Governor Christie:

As Chairperson of the Catastrophic Illness in Children Relief Fund Commission (CICRFC), it gives me great pleasure to submit to you, **The Annual Report to the Governor and the Legislature of the State of New Jersey on the Catastrophic Illness in Children Relief Fund (CICRF) Act, July 2008 to June 2009.**

In State Fiscal Year 2009, the Catastrophic Illness in Children Relief Fund Commission approved **\$8.9M** in grant awards for **363** families. Many of these families were without health care coverage at the time they incurred significant medical expenses for their children. A remarkable 92 percent of awards, however, were approved for families who were insured and still burdened with catastrophic medical expenses related to the care of their children. The diverse needs of New Jersey families continue to demonstrate the value of this unique financial safety net. Since the first grant awards were approved in December 1989 through June 2009, approximately **\$124M** was approved for more than 5,100 families in need.

The Commission continues to provide meaningful relief for families struggling to cope with the financial responsibilities which accompany a child's significant health problems. We know that you join the Commission in communicating the program's message: families do not have to bear high out-of-pocket costs for their children's care alone.

With best wishes,

Jane S. Lorber
Chairperson

EXECUTIVE SUMMARY

The Catastrophic Illness in Children Relief Fund Commission approved \$8.9M in grant awards for families in need during State Fiscal Year 2009 (SFY'09). The Commission has been providing meaningful financial relief for New Jersey families since grant awards were first approved in December 1989. As of June 30, 2009, approximately \$124M was approved for New Jersey families.

The data on awards approved in SFY'09 demonstrates that financial help was available to meet the diverse needs of 363 New Jersey families, with awards ranging from \$44 to \$100,000. The average award per family was \$23,408. Financial assistance from The Fund provided financial relief for costs associated with 349 diagnoses and conditions. Families received assistance for a wide array of medical problems, from simple fractures to rare genetic syndromes.

Knowing from experience that any family, regardless of income or insurance status, may be just one illness or accident away from personal and financial hardship, the Commission reached families through a comprehensive public information campaign. Working with volunteer parents, community and official agencies, churches, employers, and print and broadcast media, the Commission disseminated program information throughout the state.

Program expenditures are monitored, with the administrative operating cost averaging two percent over the past seven years. The Commission's cost savings initiatives, through regulatory caps and cost reduction policy, yielded savings of approximately \$1.5M in SFY'09. Since the inception of The Fund, the Commission achieved almost \$16M in total discounts. This effort continues a long-standing practice of the Commission to reduce costs, whenever possible, while ensuring a positive impact on the service to families.

The Commission looks forward to continuing service for New Jersey families, making a difference in the lives of the parents and children faced with extraordinary medical debt.

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ACKNOWLEDGEMENTS

The Catastrophic Illness in Children Relief Fund Commission (CICRFC) would like to thank the New Jersey Department of Human Services for administrative support. The Commission acknowledges the contributions of member designees in SFY'09, including:

William A.B. Ditto of the NJ Department of Human Services

Pauline Lisciotto of the NJ Department of Health and Senior Services

Hans Goft of the NJ Department of Treasury

Ellen DeRosa of the NJ Department of Banking and Insurance

Robert Morgan, M.D. of the NJ Department of Children and Family Services

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

The Catastrophic Illness in Children Relief Fund ("The Fund")

The Fund was established by legislation 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 expenses.

Eligibility Requirements

The definition of a catastrophic illness in this program is economic and is measured in terms of the financial consequences of health care expenses on the family, rather than on traditional diagnostic classifications or acuity of illness. A "catastrophic illness" means any illness or condition in which the incurred medical expenses are not covered by any state or federal program, insurance contract, or other resource, and exceeds an established eligibility threshold. In State Fiscal Year 2009 (SFY'09), a "catastrophic illness" was defined in statute to mean uncovered expenses incurred in the care of a child, which exceeded 10 percent of the first \$100,000 of annual income of a family, plus 15 percent of any excess income over \$100,000.

In SFY'04, the enabling legislation was amended to expand the age of a "child" to include someone 21 years of age and younger, so that The Fund could continue to provide continuity in financial assistance for the young adult population. In SFY'09, the Commission provided assistance to fifty-one young adults between the ages of 18 and 21.

The family must be a resident of New Jersey for at least three months prior to submission of an application. Temporary residents, including those coming to this state seeking medical care, are excluded from eligibility with the exception of migrant workers.

Income and expenses are measured for the prior consecutive 12-month period in which the expenses were incurred. The Fund is unique in that it reviews expenses on a retroactive basis. The Fund reviews expenses for a prior consecutive 12-month period of time dating back to 1988, which is the year the statute was enacted. All expenses are reviewed by the Commission and are subject to established caps and program regulations.

State Significance

A summary of health insurance tables for New Jersey residents for 2006 was released by the New Jersey Department of Health and Senior Services, Center for Health Statistics. The most recent available data, derived from the *Current Population Survey: Annual Demographic File, 2003-2007, Bureau of the Census*, estimated there were 299,274 uninsured children in New Jersey under 19 years of age. This number was reported as 13.6 percent of children in the State.

The Commission has seen that the cost of coverage remains a significant obstacle in access to public health insurance for many families in New Jersey. For families with insurance who applied for assistance, their health coverage was inadequate for the medical needs of the child.

Health insurance is tied to employment for most families; therefore, loss of employment often leads to loss of health benefits. Once a parent no longer has health coverage through a job, the family is often unable to afford the cost of health premiums. For many parents, loss of employment is a result of long hours away from work caring for a seriously ill child, driving to physician offices, and sitting in hospital rooms. With a struggling economy, jobs are harder to find, and parents are not making a seamless transition to other employment.

The cost for health care is increasing, particularly for hospital, physician, and pharmacy services. Employers are also increasingly passing on the costs for employee and/or dependent coverage to employees in the form of larger premiums, higher deductibles, and co-payments. This downgrading of benefits by employers continues to impact parents and children.

Employers who offer self-funded health plans, including unions, are covered by the federal Employee Retirement Income Security Act of 1974 (ERISA), and may offer insurance coverage that is exempt from state insurance regulation and mandated benefits. These self-funded plans provide more choice for employers in containment of health costs and increasingly appear in applications to The Fund. Some self-funded health plans previously experienced bankruptcy, indicating that this approach to health coverage can add to the volatility of the insurance marketplace.

Although subsidized health coverage for uninsured children is available through NJ FamilyCare (the federal Children's Health Insurance Program), some families may experience a lapse in coverage when a child may have uncovered medical expenses. In addition, The Fund may pay for expenses that are not covered through NJ Family Care and other State programs. The Commission has the ability to fill in these gaps and may provide financial assistance for such families.

Since its inception in 1989, the Commission has fulfilled a need in providing financial relief for families from a wide socio-economic range. A great majority of the families were employed, had some form of insurance, and yet were still vulnerable to personal and financial distress from catastrophic medical costs. Historical data supports that the Commission approved \$124M to assist over 5,100 families with health care and related expenses that were otherwise uncovered by insurance or any other resource, including, but not limited to, state or Federal funds. Remarkably, awards have ranged from \$44 to \$907,585, and family income levels span from \$0 to \$638,797. However, SFY'09 awards ranged from \$44 to \$100,000 with the family income levels spanning from \$0 to \$297,829, with an average income of \$55,195. Significant efforts have been made since The Fund's inception, and will continue to be made, to ensure that all New Jersey families are aware of The Fund's existence.

Catastrophic Illness in Children Relief Fund Commission

In January 2008, Governor Corzine signed amending legislation establishing the Commission in the Executive Branch of New Jersey State government. The Commission is allocated within the New Jersey Department of Human Services (DHS), but notwithstanding that allocation, the Commission shall be independent from any supervision or control by the Department or by any board or officer thereof. The Commission is assigned to DHS for administrative purposes.

In SFY'09, the Commission membership consisted of 12 members: five members ex officio and seven members appointed from the public by the Governor, with the advice and consent of the Senate for terms of five years. Two of the public members must be providers of healthcare services for children in New Jersey. The ex officio members are the Commissioners of DHS, the NJ Department of Health and Senior Services (DHSS), the NJ Department of Children and Families (DCF), the NJ Department of Banking and Insurance (DOBI), and the NJ Department of Treasury.

Responsibilities of the State Office of the Commission

The State Office of the Commission is responsible for administering The Fund on a day-to-day basis and maintaining

Staff in the State Office of the Commission provide guidance needed by the family to initially submit provider bills to insurance, seek Charity Care determinations, or otherwise utilize available resources before submitting an application for financial assistance. Staff provide information to families for utilizing health care services and understanding reimbursement systems.

Coordination with Special Child, Adult and Early Intervention Services

The enacting legislation requires that The Fund work in conjunction with Special Child, Adult and Early Intervention Services (SCAEIS) in DHSS. The Commission has continued its grant to SCAEIS for contracted services from the Special Child Health Services (SCHS) Case Management Units in each county to ensure families have access to program information and referral at a more local level.

Public Information

In SFY'09, the Commission's Public Information Plan was designed to enhance public awareness of The Fund through paid advertising, community outreach and public relations efforts. The distinct and creative designs, which identify the Program, were re-designed with input from Winning Edge Communications (WEC), staff and the Commission's Executive Director. New tri-fold informational fliers were printed in both English and Spanish. WEC was awarded the contract to become the new advertising/public relations firm for The Fund, effective October 22, 2007 and terminating October 31, 2010. The unique 800-phone number continued to be available to the public as the Family Information Line, 1-800-335-FUND. The Fund's website is also available for the public, www.njcatastrophicfund.org.

Emphasis this year shifted to a concerted effort to get the name and number of The Fund more visible to the public eye. Vital to this campaign was the posting of bus kings advertising in several New Jersey counties and on transportation routes close to major medical centers and children's hospitals. The presentations to groups not familiar with The Fund or those who are in contact with families continued, as well as exhibits at conferences and conventions. The campaign followed up with community organizations, schools, individual families and small groups representing parents with disabled children.

The Commission's Annual Meeting was held on June 24, 2009, where the Commission joined the Family Advisory Committee (FAC) and guests. The meeting, held in the War Memorial Building, was attended by honored guests including Governor Jon Corzine, DHS Commissioner Jennifer Velez, Commission members, staff, and many families and applicant children. The FAC supports the Commission in disseminating program information on the local level. Many television stations ran media spots of this important event. In SFY'09, the FAC had 87 active families.

Collection and Accounting of the Fund

In accordance with the provisions of *P.L. 1987, C.370*, the Commission is responsible for assessing a \$1.50 annual surcharge per employee for all employers subject to the New Jersey Unemployment Compensation Law, *R.S. 43:31-1 et seq.* The surcharge is collected to provide revenue to meet the purposes of The Fund. The surcharge is collected by the State Department of Labor and Workforce Development (LWD) and paid over to the State Treasurer for deposit into The Fund. The interest earned on the money collected is credited to The Fund.

CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND
Fund Balance

	ACTUAL FY'08	ACTUAL FY'09
REVENUES:		
FUND BALANCE JULY 1	\$ 4,000,442	\$6,047,787
SERVICES AND ASSESSMENTS	\$ 9,895,201	\$8,959,711
INVESTMENT EARNINGS	\$ 184,404	\$ 61,473
TOTAL REVENUE	\$ 14,080,047	\$15,068,971
EXPENDITURES:		
PHYSICAL AND MENTAL HEALTH	\$ (103,737)	\$ (105,812)
GOV DIRECTION, MANAGEMENT & CONTROL	\$ (6,637,092)	\$ (7,803,530)
OPERATING EXPENSES	\$ (1,291,431)	\$ (1,200,686)
TOTAL EXPENDITURES	\$ (8,032,260)	\$ (9,110,028)
OTHER FINANCIAL USES:		
Due to the budget crisis, there was a diversion of funds from our account in the amount of \$5M.		
TOTAL OTHER FINANCIAL USES	\$ ---	\$(5,000,000)
TOTAL EXPENDITURES & OTHER FINANCIAL	\$ (8,032,260)	\$ (14,110,028)
FUND BALANCE JUNE 30	\$ 6,047,787	\$ 958,943

Financial Statements on revenue, expenditures and other financial issues of The Fund were prepared utilizing figures provided by the State Department of Treasury and annotated by fiscal staff of the Catastrophic Illness in Children Relief Fund Commission.

In SFY'09, the Commission processed 459 applications. Of those applications, the Commission approved \$8.5M for 363 families. In addition, 36 referrals were made for 28 families who may benefit from other state resources. Ninety-six applications did not meet The Fund's financial eligibility threshold.

TOTAL AWARDS APPROVED	\$8.9M
TOTAL APPLICATIONS APPROVED	363
Range of Awards	\$44 - \$100,000
Average	\$23,408
Range of Income	\$0 - \$297,829
Average	\$55,195
Average Expense: Income	42%

The applications reviewed by the Commission reflected a range of uncovered expenses among families in need. Awards approved by the Commission in SFY'09 ranged from \$44 - \$100,000, with an average award of \$23,408. Similarly, the range of expense-to-income threshold was as dramatic as the range in awards.

The range of income status of applicant families continues to increase. Families with higher incomes realize that The Fund is a viable resource when uncovered medical expenses become proportionately high for them. (See Chart)

CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION
AWARDS BY INCOME
SFY'09

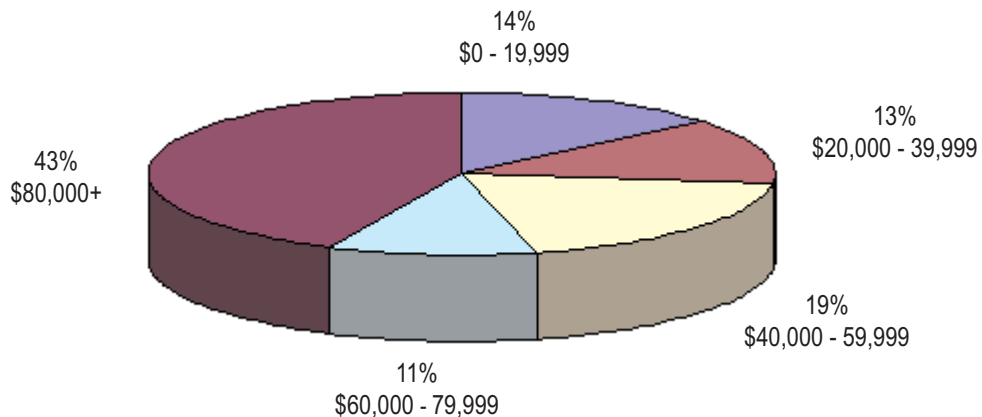


Table 1

**CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION
APPLICATIONS BY COUNTY IN SFY'09**

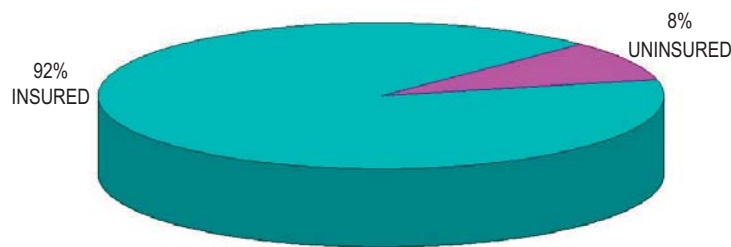
COUNTY	TOTAL REVIEWED	ELIGIBLE	INELIGIBLE	EXPENSES	COMMISSION APPROVED	FUND DISTRIBUTION
ATLANTIC	13	9	4	148,906	148,906	144,324
BERGEN	54	44	10	924,361	898,559	840,013
BURLINGTON	23	19	4	571,668	541,485	517,799
CAMDEN	28	23	5	500,674	500,674	471,885
CAPE MAY	3	2	1	19,315	19,315	19,315
CUMBERLAND	2	1	1	5,562	5,562	5,562
ESSEX	23	17	6	524,403	524,403	521,661
GLOUCESTER	23	19	4	402,922	402,992	367,534
HUDSON	14	8	6	116,256	116,256	100,508
HUNTERDON	4	3	1	56,313	56,313	56,313
MERCER	6	5	1	38,475	38,475	38,475
MIDDLESEX	30	23	7	1,282,010	1,037,038	667,785
MONMOUTH	33	25	8	1,078,959	823,032	754,772
MORRIS	30	21	9	671,239	661,684	625,972
OCEAN	72	66	6	834,491	834,491	795,665
PASSAIC	33	28	5	595,048	595,048	548,897
SALEM	1	1	0	7,615	7,615	7,615
SOMERSET	19	10	9	201,703	201,703	199,419
SUSSEX	12	9	3	306,045	306,045	301,248
UNION	28	22	6	981,685	981,685	808,076
WARREN	8	8	0	194,996	194,996	178,560
OUT OF STATE	0	0	0	0	0	0
TOTALS	459	363	96	\$9,462,646	\$8,896,277	\$7,971,398

*Utilization of regulatory caps combined with standardized discounts saved The Fund approximately \$1.5M in SFY'09.

Insurance Status of Eligible Parents, SFY'09

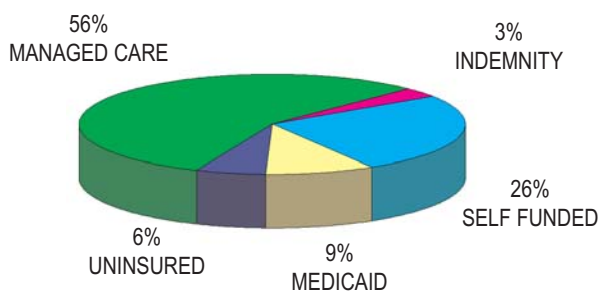
Some form of insurance covered the majority of families eligible for assistance, regardless of employment status. More than 92 percent of the families were insured and still had extraordinary out-of-pocket expenses incurred in the care of a child. (See Chart)

UNINSURED ELIGIBLE POPULATION, SFY'09

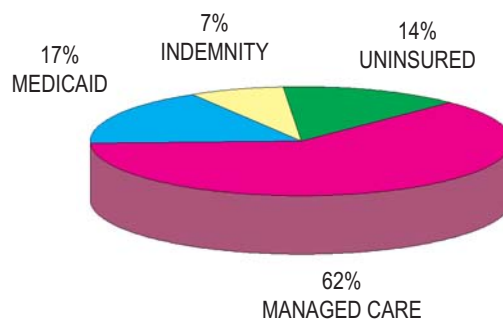


An analysis of applications by employment status reflects that the majority of the employed and self-employed parents was insured by private insurance, Medicaid, or both. Of the employed parents, three percent were covered by indemnity plans, 56 percent were covered by managed care, 26 percent were covered by self funded, and nine percent had children who were covered by Medicaid. Self-funded plans represent a combination of health plans that are outside the regulatory jurisdiction of DOBI and DHSS. They may include, but are not limited to, trade unions and most self-funded employer groups that have an ERISA exemption, which excludes them from offering the state mandated benefits as part of their insurance plans. Of the self-employed parents, seven percent were covered by indemnity plans, 62 percent were covered by managed care, and 17 percent had children who were covered by Medicaid; none of these families were covered by self-funded plans. The uninsured for each group reflects six and fourteen percent, respectively. (See Charts)

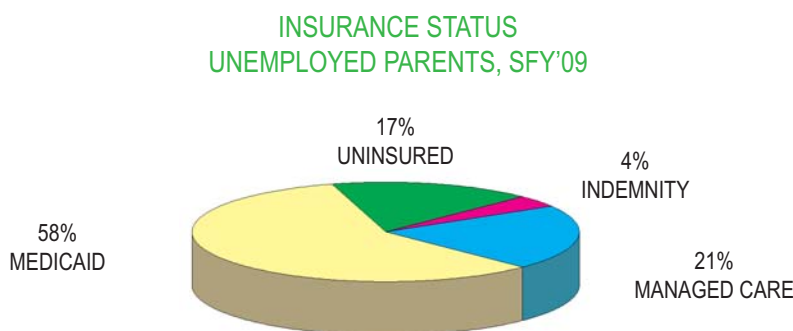
INSURANCE STATUS
EMPLOYED PARENTS, SFY'09



INSURANCE STATUS
SELF-EMPLOYED PARENTS, SFY'09



The unemployed parents eligible for assistance from The Fund confirms that insurance is connected to employment. Of this group, 21 percent were covered by managed care, 4 percent were covered by indemnity plans, and 58 percent had Medicaid coverage for the child. The uninsured in this group of parents was 17 percent. Some parents, though unemployed, were able to continue insurance through the Consolidated Omnibus Budget Reconciliation Act (COBRA) when it was available and affordable. Others had insurance coverage available only for a short period of time after employment ended. Many were uninsured, as they were unable to purchase insurance directly due to the high cost of self-pay coverage. (See chart below):



Families who continue to be uninsured at the time the Commission reviews an application are referred by the State Office of the Commission to appropriate state agencies for information on available insurance products and government programs. Families who appear eligible for other programs are referred as well.

Public Need for the Fund

In SFY'09, 363 eligible families sought assistance for uncovered expenses due to a variety of circumstances. Assistance offset expenses for the following general categories*:

- 2% Pre-existing condition
- <1% Lack preauthorization
- 33% Expenses exceeded charges allowed by insurance
- 73% Non-covered services

(*more than one hundred percent, as some families were eligible based on more than one category).

In SFY'09, 27 families eligible for financial assistance were uninsured. This represents seven percent of all the eligible families. The Commission anticipates a continued demand for The Fund by parents whose expenses were incurred during a break in health insurance coverage. In SFY'09, the Commission reviewed one application for expenses dating back to 1999. It may review expenses dating back to 1988.

Review of Appeals

In SFY'09, the Commission reviewed ten appeals and reversed the initial determination of ineligibility for three applications.

Review of Health Insurance Premiums and Impact On The Fund

At the request of the Commission, a staff member reviewed all cases (n=148) in which health insurance premiums were an eligible expense under The Fund during SFY'09. The following summarizes the findings of this review:

Total awards (with and without health insurance):	\$8,896,277
Total reimbursement for all services (in cases with health insurance only):	\$3,285,979
Total reimbursement for health insurance only:	\$361,558

Health insurance costs accounted for 11 percent of all eligible expenses only in cases that included health insurance as a cost, but only accounted for 4 percent of all eligible costs in all cases. Health insurance costs ranges from \$57 - \$8,683, with an average cost of \$2,443. It was noted that 22 of the 148 cases (17 percent) had adjusted health insurance costs. In these cases, staff has used an adjusted figure to calculate reimbursement, as per our regulations, which state that we may consider up to one-half of eligible health insurance premium costs. However, should the cost of fifty percent of the health insurance premiums exceed fifty percent of all eligible expenses, staff must use the lesser amount, called an “adjusted health insurance premium.”

Adjusted health insurance costs totaled \$87,136 during SFY'09, ranging from \$998- \$8,683 with an average cost of \$3,961. This is \$1,518 more than average total cost as compared to unadjusted health insurance.

In 126 of the 148 cases (83 percent), staff was able to use the actual health insurance expenses. In these cases, which totalled \$274,422, there was a range of \$57 - \$7,937, and an average actual cost of \$2,178 (\$265.00 less than average total cost). Twenty-four of the 148 cases (17 percent) would have been ineligible for any Fund assistance without their health insurance premium costs.

Review of Categories of Eligible Health Services

The Fund considers a broad range of health services, including medical and other services, which 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/lease of a specialized, modified vehicle to accommodate a child’s disability and modifications to subsequent vehicles purchased by a family. The Fund does not reimburse for special education services required as a result of medical condition or elective cosmetic surgery.

Chapter 10:155 identifies the categories of health services that are considered as eligible, 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 SFY'09.

Category of Eligible Health Service	Average	Category of Eligible Health Service	Average
Transportation	26%	Pharmacy	2%
Hospital, In-State	24%	Disposable Medical Supplies	< 1%
Home Modification	10%	Funeral Expenses	< 1%
Specialty Hospital, Out-Of-State	10%	Ancillary Services	< 1%
Physician Services	9%	Home Health Care	< 1%
Hospital, Out-of-State	7%	Temporary Shelter	< 1%
Specialized Pediatric Ambulatory Care	6%	Long Term Care	< 1%
Health Insurance	4%	Telephone	< 1%
Durable Medical Equipment	3%	Experimental Services	0%
Specialty Hospital, In-State	2%		

Review of Medical Conditions

Families apply to the Catastrophic Illness in Children Relief Fund for their children's medical expenses, which result from an illness or health related condition. The illness or condition is assigned the appropriate diagnostic code based on Ingenix EncoderPro.com, a web-based service.

Encoder Pro provides the International Classification of Diseases World Health Organization's Ninth Revision, Clinical Modifications ICD-9-CM codes and descriptions based on the official U.S. Department of Health and Human Services ICD-9-CM codes effective each current year. ICD-9-CM classifies morbidity and mortality information for statistical purposes, indexing of hospital records by disease and operations, data storage and retrieval. It is designed with precise codes and a classification system that indexes health related conditions, diseases, and procedures, which help describe the clinical picture of the person and is used to classify morbidity data when compiling basic health statistics. The codes can contain up to five digits whenever a greater specificity of a diagnosis is required.

The ICD-9-CM is based on the official version of the Ninth Revision, International Classification of Diseases (ICD-9).

The next page provides an unduplicated list of diagnoses and conditions presented to the Commission in SFY'09. The list is comprised of both physical and mental health diagnoses, which have generated medical expenses, deemed eligible by the Catastrophic Illness in Children Relief Fund Commission.

Catastrophic Illness in Children Relief Fund Commission
Unduplicated List of Diagnoses/Conditions
In SFY'09 Eligible Applications

Diagnoses (N=349)	Code	Diagnoses (N=349)	Code
Abrasion or friction burn without mention of infection	919.0	Atrial septal defect	745.5
Acquired hydrocephalus not otherwise specified	331.4	Attention deficit disorder with hyperactivity	314.01
Acrocephalosyndactyly	755.55	Autistic disorder	299.0
Acute appendicitis	540	Autistic disorder, current or active state	299.00
Acute appendicitis, with perforation	540.0	Autoimmune hepatitis	571.42
Acute bronchitis	466	Bilateral cleft palate with cleft lip, complete	749.23
Acute chest syndrome	517.3	Bipolar disorder, unspecified	296.80
Acute lymphoid leukemia	204.0	Bipolar I disorder, most recent episode depressed; severe	296.53
Acute lymphoid leukemia, in remission	204.01	Blindness and low vision	369
Acute lymphoid leukemia, without mention of remission	204.00	Bronchial asthma	493.9
Acute renal failure	584	Bulimia nervosa	307.51
Acute renal failure, unspecified	584.9	Burkitt's tumor or lymphoma	200.2
Acute respiratory failure	518.81	Cannabis dependence, episodic abuse	304.32
Acute upper respiratory infections of multiple or unspecified sites	465.9	Cardiac arrest of newborn	779.85
Adjustment disorder with anxiety	309.24	Cardiac dysrhythmia, unspecified	427.9
Adjustment reaction	309	Cardiomyopathy	435
Aggenesis of the corpus collosum	742.2	Celiac disease	579.0
Alternating esotropia	378.05	Cellulitis and abscess of upper arm and forearm	682.3
Alternating exotropia	378.15	Central sleep apnea	327.21
Anaplastic large cell lymphoma	200.6	Cerebral dysgenesis	742.88
Anemia of neonatal prematurity	776.6	Cerebral palsy	343
Anomalies of the cerebrovascular system	747.81	Cerebral palsy, diplegic	343.9
Anorexia nervosa	307.1	Cerebral palsy, infantile, unspecified	343.0
Anxiety disorder, unspecified	300.0	Cerebral palsy, quadriplegic	343.2
Anxiety states	300.00	Cerebral thrombosis with cerebral infarction	434.01
Aortic valve disorders; regurgitation	424.1	Chronic respiratory disease arising in the perinatal period	770.7
Apraxia	784.69	Chronic serous otitis media	381.1
Arthralgia	719.14	Chronic sinusitis	473
Arthrogyposis	728.3	Chronic tonsillitis and adenoiditis	474.0
Aseptic necrosis of bone	733.4	Cleft lip	749.1
Asthma	493	Cleft palate	749.0
Asthma, unspecified	493.9	Cleft palate with cleft lip	743.23
Athetoid cerebral palsy	333.71	Cleft palate with cleft lip, bilateral, incomplete	749.24
Atresia of small intestine, not otherwise specified	751.1	Closed dislocation of hip, unspecified site	835.00

Diagnoses (N=349)	Code	Diagnoses (N=349)	Code
Closed fracture, upper end of tibia	823.00	Disorders of the pituitary gland and its hypothalamic control	253
Combined immunity deficiency	279.2	Disturbance of amino acid transport	270.0
Common ventricle	745.3	Disturbances in tooth eruption	520.6
Complication due to internal orthopedic implant	996.67	Double outlet right ventricle	745.11
Complications of transplanted organ, liver	996.82	Down syndrome	758.0
Complications of transplanted organ, bone marrow	996.85	Duchenne muscular dystrophy	359.1
Conductive hearing loss, unspecified	389.00	Dysgraphia	781.3
Congenital anomalies of respiratory system	748	Dysphagia	787.2
Congenital hypertrophic pyloric stenosis	750.5	Eating disorder, unspecified	307.50
Congenital mitral stenosis	746.5	Ehlers-Danlos syndrome, severe	756.83
Congenital hydrocephalus	742.3	Encephalitis	323.0
Congestive heart failure	428.0	Encephalopathy, other	348.39
Convulsions	780.3	Encephalopathy, unspecified	348.30
Cortical blindness	377.75	Eosinophilic esophagitis	530.13
Cortical visual impairment	369	Eosinophilic gastroenteritis	558.41
Crouzon's disease	756.0	Esophageal reflux	530.81
Cystic fibrosis	277.0	Esophagitis, unspecified	530.10
Cystic hygroma	228.1	Essential hypertension, unspecified	401.9
Cytomegaloviral disease	078.5	Extreme fetal immaturity, 1500-1749 grams	765.06
Cytophagic histiocytic panniculitis	729.3	Extreme immaturity	765.22
Delay in development, unspecified	315.9	Extrinsic asthma	493.0
Delayed milestones	783.42	Failure to thrive	783.41
Dental caries	521.0	Familial dysautonomia	742.8
Dentofacial anomalies including malocclusion	524	Feeding difficulties	783.3
Depressive disorder, not elsewhere classified	311	Feeding disorder of infancy	307.59
Developmental delays	783.4	Feeding problems in newborn	779.3
Developmental disorder, not otherwise specified	315.9	Fracture of femur	821.01
Developmental odontogenic dentigerous cyst	526.0	Fracture of unspecified bones of the foot	825.30
Diabetes mellitus	250	Fracture of vertebral column with spinal cord injury	806
Disorder of calcium metabolism	275.4	Fragments of torsion dystonia	333.8
Disorders of amino acid transport and metabolism	270.0	Freeman-Sheldon syndrome	759.89
Disorders of carbohydrate transport and metabolism	271	Friedreich's ataxia	334.0
Disorders of fluid, electrolyte, acid-base balance; acidosis	276.2	Generalized anxiety disorder	300.02
Disorders of mitochondrial metabolism	277.87	Generalized convulsive epilepsy	345.1

Diagnoses (N=349)	Code	Diagnoses (N=349)	Code
Generalized nonconvulsive epilepsy	345	Lupus erythematosus	695.4
Generalized nonconvulsive epilepsy with intractable epilepsy	345.01	Lyme disease	088.81
Geroderma osteodysplastica	756.6	Lymphangioma, any site	228.1
Giant congenital melanocytic nevus	216.3	Lymphoid leukemia, acute	204.0
Hearing loss, unspecified	389.9	Lymphoma	202.80
Heart murmurs, not otherwise specified	785.2	Macrocephaly	742.4
Hemiplegic infantile cerebral palsy	343.1	Macrophage activation syndrome	288.4
Hereditary peripheral neuropathy	356.0	Major anomaly of jaw size, unspecified anomaly	524.00
Hereditary progressive muscular dystrophy	359.1	Major depression, recurrent, without psychosis	296.33
Hereditary spherocytosis	282.0	Major depressive disorder, recurrent episode, moderate	296.32
Hirschsprung's disease; other congenital functional disorder of colon	751.3	Malignant neoplasm of bone and articular cartilage	170
Hodgkin's disease	201	Malignant neoplasm of brain	191
Human immunodeficiency virus disease	042	Malignant neoplasm of cerebrum	191.0
Hurler's syndrome (mucopolysaccharidosis)	277.5	Malignant neoplasm of spinal cord	192.2
Hydronephrosis	591	Malignant neoplasm of stomach	151
Hyperacusis	388.42	Malocclusion, Angle's class II	524.22
Hyperkinetic syndrome of children, with hyperactivity	314.01	Maxillary hypoplasia	524.03
Hypertensive encephalopathy	437.2	Mental retardation	319
Hypertrophy, adenoids alone	474.12	Mental retardation, profound	318.2
Hypoplastic left heart syndrome	746.7	Mental retardation, severe	318.1
Hypothyroidism	244	Metachromatic leukodystrophy	330.0
Hypotonia	781.3	Microcephalus	742.1
Hypoxic-ischemic encephalopathy	768.7	Microtia	744.23
Idiopathic peripheral autonomic neuropathy	337.0	Migraine	346
Idiopathic scoliosis	737.30	Mitochondrial disorder	277.87
Idiopathic transverse myelitis	341.22	Mixed receptive-expressive language disorder	315.32
Inguinal hernia	550	Motor incoordination	781.3
Insomnia with sleep apnea	780.51	Moyamoya syndrome	437.5
Intracranial injury of other unspecified nature	854	Multiple fractures involving both lower limbs and ankles	828
Intraventricular hemorrhage	772.11	Multiple pelvic fracture	808.43
Joubert syndrome	759.89	Multiple sclerosis	340
Kidney abscess	590.2	Muscle weakness (severe hypotonia)	728.87
Kidney infection	590.9	Muscular dystrophies and other myopathies	359
Lack of normal physiological development, unspecified	783.40	Muscular dystrophy	359.1
Leigh's disease	330.8	Myasthenia gravis	358.0
Lump or mass in breast	611.72	Myopia	367.1

Diagnoses (N=349)	Code	Diagnoses (N=349)	Code
Nemaline myopathy	359.0	Other pre-term infants, 33-34 completed weeks gestation	765.27
Neonatal jaundice associated with pre-term delivery	774.2	Other pre-term infants, 35-36 completed weeks gestation	765.28
Neoplasm of the brain	225.0	Other pre-term infants, 37 or more completed weeks gestation	765.29
Neoplasms of unspecified nature; other specified sites	239.8	Other pre-term infants, unspecified	765.10
Nephrotic syndrome	581	Other respiratory problems after birth	770.89
Neurogenic arthrogyposis	728.3	Other specified anomalies of nervous system	742.8
Neurogenic bladder, not otherwise specified	596.54	Other specified cerebral degenerations in childhood	330.8
Non-infectious gastroenteritis	558	Other specified conditions originating in the perinatal period	779.8
Nonspecific abnormal results of function studies; liver	794.8	Other specified hemiplegia affecting unspecified side	342.80
Nystagmus and other irregular eye movements	379.5	Other specified multiple congenital anomalies	759.89
Obsessive-compulsive disorder	300.3	Other symbolic dysfunction	784.69
Obstructive hydrocephalus	331.4	Other symptoms involving respiratory and other chest symptoms	786.09
Open transcervical fracture right femur and tibia/fibula	820.1	Otitis media	381
Open wound of knee without mention of complication	891.0	Paraplegia	344.1
Oppositional defiant disorder	313.81	Patent foramen ovale	745.59
Orbital cellulitis	376.01	Pelizaeus-Merzbacher disease	330.0
Osteoarthritis, unspecified, pelvic region and thigh	715.95	Perforation of intestine	569.83
Other symbolic dysfunction	784.6	Peritonsillar abscess	475
Other adverse food reactions, not elsewhere classified	995.7	Periventricular leukomalacia	779.7
Other and unspecified congenital abnormalities	759.89	Persistent pulmonary hypertension	747.83
Other and unspecified disorders of bone and cartilage	733.90	Persistent vegetative state	780.03
Other and unspecified disorders of eating	307.59	Persistent vomiting	536.2
Other and unspecified noninfectious gastroenteritis and colitis	558.9	Pervasive developmental disorder	299
Other condition of brain; calcification	348.8	Pervasive developmental disorder, Asperger's	299.80
Other conditions due to chromosomal anomalies	758.8	Phenylketonuria (PKU)	270.1
Other convulsions	780.39	Phonological disorder	315.39
Other disorders of bone and cartilage	733	Plagiocephaly	754.0
Other disorders of eyelids	374	Pneumococcal pneumonia	481
Other disturbances of aromatic amino-acid metabolism	270.2	Pneumonia, organism unspecified	486
Other encephalopathy	348.39	Post-traumatic stress disorder	309.81
Other ovarian hyperfunction	256.1	Prematurity 27-28 weeks	765.24
Other paralytic syndrome	344	Prematurity not otherwise specified	765.1
Other pre-term infants, 24 completed weeks gestation	765.22	Prematurity, completed 25-26 weeks gestation	765.23
Other pre-term infants, 2500 or more grams	765.19	Prematurity, completed 31-32 weeks gestation	765.26

Diagnoses (N=349)	Code	Diagnoses (N=349)	Code
Primary apnea of newborn	770.81	Systemic lupus erythematosus	695.4
Primary pulmonary hypertension	416.0	Talipes equinovarus	754.51
Profound mental retardation	318.2	Tear film insufficiency, unspecified	375.15
Progressive infantile idiopathic scoliosis	737.32	Testicular torsion, unspecified	608.20
Pseudotumor cerebri, benign intracranial hypertension	248.2	Tetralogy of Fallot	745.2
Rape	E960.1	Tongue tie	750.0
Reactive airway disease	493.90	Torticollis	723.5
Reduction deformities of brain	742.2	Toxic shock syndrome	040.82
Reflux esophagitis	530.11	Tracheal stenosis	748.3
Respiratory distress syndrome	769	Transient cerebral ischemia	435
Retinopathy of prematurity, not otherwise specified	362.20	Transposition of great vessels - double outlet right ventricle	745.11
Rett syndrome	330.8	Traumatic brain injury, unspecified	854
Schizoaffective disorder, unspecified	295.70	Tuberous sclerosis	759.5
Schizophrenia, catatonic type	295.2	Ulcerative colitis	556.9
Scoliosis, idiopathic	737.30	Undescended testis	752.51
Sensorineural hearing loss	389.1	Unilateral, incomplete cleft lip	749.12
Sensorineural hearing loss, unspecified	389.10	Unspecified anomaly of the heart	746.9
Septicemia of newborn	771.81	Unspecified cerebral artery occlusion with cerebral infarction	434.91
Serous otitis media	381.10	Unspecified episodic mood disorder	296.60
Severe mental retardation	318.1	Unspecified fetal and neonatal jaundice	774.6
Sickle cell disease, Hb-SS disease with crisis	282.62	Unspecified intestinal malabsorption	579.9
Sickle cell disease	282.6	Unspecified obstructive defect of renal pelvis and ureter	753.20
Sleep apnea	780.57	Unspecified otitis media	382.9
Sleep related hypoventilation/hypoxemia in condition classified elsewhere	327.26	Unspecified peripheral neuropathy	356.9
Spasm of muscle	728.85	Unspecified pervasive developmental disorder	299.9
Spastic hemiplegia affecting non-dominant side	342.12	Unspecified sensorineural hearing loss	389.10
Spina bifida	741	Urinary tract infection	599.0
Spina bifida with hydrocephalus	741.03	VATER syndrome	759.89
Spina bifida with hydrocephalus, lumbar region	741.0	Ventricular septal defect	745.4
Spinal muscular atrophy	335.1	Verbal apraxia	784.69
Sprain/strain cruciate ligament of knee	844.2	Vesicoureteral reflux	593.7
Stenosis of larynx	478.74	Viral gastroenteritis	008.8
Stress fracture of the fibula	733.3	Viral meningitis	047
Subaortic stenosis	746.81	Visual impairment	369.0
Syringomyelia	336.0	Voice disturbance, other	784.49

Diagnoses (N=349)	Code
Volvulus	560.2
Von Willebrand's disease	286.4
Werdnig-Hoffmann disease	335.0

Fiscal Issues

The Commission continued prudent fiscal practices in SFY'09 that preserved resources for families applying for financial assistance. In addition to implementing various regulatory caps, staff continued the practice of successfully negotiating discounts on all large balance accounts. All families were held harmless from any of these balances. Implementation of these regulatory and non-regulatory provisions realized savings of approximately \$1.5M in SFY'09. (See Table 1, page 11). Since the discount policy was adopted, the Commission realized savings of approximately \$16M.

In January 2008, Governor Corzine signed amending legislation establishing the Commission in the Executive Branch of the New Jersey State government. The Commission voted to support new legislation that would increase the assessment from \$1 per employee to \$1.50. In previous discussions, the Commission received bipartisan support of this proposal. The administration as well as all other stakeholders including the New Jersey Business and Industry Association supported the fee increase. In May 2007, State Senators Vitale and Rice sponsored S.2633, which increased the assessment; the first increase in the funding mechanism in the history of The Fund. This increase enables the Commission to continue to meet its mandate by providing financial assistance to families. Additionally, the bill memorializes the Commission's independent status.

With the support of U.S. Senator Lautenberg, the State Office of the Commission has reached out to the federal government to explore the possibility of receiving financial support for its federal employees who work in New Jersey. Approximately 61,000 civilian military employees and 11,000 federal employees work in New Jersey, and the federal government may make its first contribution to The Fund.

Public Information Efforts

The Fund has seen a significant increase in the number of requested and received applications. In SFY'09, a new general service announcement (GSA) was produced, featuring Kelly Rouba, a former recipient of The Fund. Program information requests were generated from a variety of sources, including but not limited to health care providers, schools, special children's programs, friends and other State programs. The Fund also continues to receive requests for information through the new website, www.njcatastrophicfund.org. On this site, interested parties can access information about The Fund, including a copy of our Annual Report. Information about The Fund can also be accessed through the 211 information and referral system, as well as through web links at various organizations and companies, including but not limited to Virtua Health Systems, Parent Partners Muscular Dystrophy, and the CARES Foundation. The online screening tool of NJ Helps, Phase II is operational. NJ Helps takes basic information from a user and generates appropriate program referrals; it is hoped that this online tool will generate new referrals to The Fund as well.

Outreach efforts continued throughout the fiscal year. The Fund attended and/or exhibited at several conferences and fairs, including the NJ Conference of Mayors, the Regional Family Support Council's Provider Fair, the NJ Association of Counties 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, and communities identified through our newspaper clipping service and reporters of stories on ill children.

In the past, many of the applications received from families were initiated by providers. It was decided that The Fund would expand outreach efforts in an attempt to reach those families who have high uncovered medical expenses from various sources rather than from one major provider. Since then, The Fund has made an effort to target advertising and educational materials towards families and small grassroots organizations, in order to facilitate more direct family reimbursements.

In July 2008, letters were sent to recent recipient families, inviting them to participate as volunteer members of the Commission's Family Advisory Committee (FAC) in order to assist the Commission in disseminating program information at the local level. Letters were also sent to existing FAC members, asking if they wished to continue participation, based on their interest and availability.

A new, simplified version of the program's application has been created and will be implemented in SFY'10. It includes a one-page initial application screening tool rather than the previous eight page application. Once preliminary eligibility is established, the family will receive a document requesting further information. The goal is to have the initial application posted on the program's website.

Testimonials

Families from all economic backgrounds applied for assistance and were extremely thankful for their financial support. The following testimonials from recipient families validate the success and effectiveness of The Fund:

"From day one, when we called [the Fund], we felt hope, we felt so much concern for our situation, so much courtesy, so much respect, and most importantly, such genuine desire to help... I want to express our enormous gratitude to [the Commission] for the help, for giving us hope of regaining confidence in our future, for making us feel that we are not alone in this world." (Essex County - parents of a 16-year-old)

"It is difficult for us to put into words how grateful we are for your financial support. The last few years for our family have been extremely trying. Your [Fund's] financial reimbursement for our medical expenses has been a saving grace and will afford us the ability to stay in our house." (Bergen County – parents of a 3-year-old)

"[Your] help has been appreciated. There aren't many people in this world that [hold] your hand when you're down. We also want to thank everyone in [the Fund]. Help came when needed the most." (Morris County – parents of a 17-year-old)

"We want you to know that this program is essential and that your hard work is really making a difference ... Our family hopes that this program will continue and that you all will be commended for your dedication. Thank you again and again." (Burlington County – parents of a 2-year-old)

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 have become catastrophic for that family. Due to the fact that The Fund assists such a broad segment of the population, it is not possible to focus on a limited audience for dissemination of public information. Rather, it is necessary to identify a variety of target audiences involved with children's issues and to diversify advertising efforts as efficiently and cost effectively as possible in order to reach those audiences statewide.

There continues to be a pressing need for the assistance of 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 of our New Jersey families.

The public needs program information to be available directly as well as through traditional sources of information, such as: health care providers, state, and community organizations. The Commission's Public Information Plan in SFY'09 provided for such dissemination of information.

Combined efforts by the Commission, staff, FAC volunteer parents and advertising vendors provided the public with access to information on the valuable state resource of the Catastrophic Illness in Children Relief Fund. With an active Public Information Plan in place, the Commission is committed to publicizing to its expanding population.

§ 26:2-148. Legislative findings and 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, § 1.

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

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, § 2; amended 1993, c. 103, § 1; 1998, c. 143, § 1, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998; 2003, c. 260, § 1, eff. Jan. 14, 2004.

§ 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, § 3.

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

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 and Senior Services, 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 his department to represent him 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, § 4; amended 1993, c. 103, § 2; 1994, c. 149, § 1; 1998, c. 143, § 2, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998; 2006, c. 47, § 105, eff. July 1, 2006; 2007, c. 342, § 1, eff. Jan. 13, 2008.

§ 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, § 5.

§ 26:2-153. Officers; quorum

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, § 6; amended L. 1994, c. 149, § 2.

§ 26:2-154. Powers; duties

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, § 7; amended 1998, c. 143, § 3, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998; 2003, c. 260, § 2, eff. Jan. 14, 2004.

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

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, § 3.

§ 26:2-155. Eligibility

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 this act.

L. 1987, c. 370, § 8; amended 1998, c. 143, § 4, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998.

§ 26:2-156. Financial assistance

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, § 9; amended 1998, c. 143, § 5, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998; 2003, c. 260, § 3, eff. Jan. 14, 2004.

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

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, § 10; amended 2007, c. 342, § 2, eff. Jan. 13, 2008.

§ 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, § 11.

§ 26:2-159. Annual reports

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, § 12; amended 1998, c. 143, § 6, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998.

§ 10:155-1.1 Purpose and scope

(a) The purpose of this subchapter is to establish criteria for eligibility and 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 suffers from a catastrophic illness.

(b) The procedures established 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, 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 not covered by any other State or Federal program or any other insurance contract or trust which allows funds to provide for the medically related needs of a child as defined in N.J.A.C. 10:155-1.14 or settlement relative to the medical condition of a child exceed 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 greater than 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 NJ Department of Personnel's 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 insurance" means contracts, excluding automobile insurance contracts, whereby an insurer is obligated to pay or allow a benefit for the child as a named insured 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 dental, vision, and prescription drug.

"Income" means the following:

1. Wages before deductions;
2. Public Assistance;
3. Social Security Benefits;
4. Supplemental Security Income;
5. Unemployment and Workman's 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,
21. 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 agency 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 (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.

"Threshold" means the point at which a child's out-of-pocket medical expenses exceed 10 percent of the first \$100,000 of annual income of a family plus 15 percent of the excess income over \$100,000. After the child's medical expenses reach this threshold, a child has passed the initial screen for eligibility for assistance from the Fund.

§ 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 represented by 10 per-cent 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 initial 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 residents in New Jersey are excluded from eligibility. Seasonal or temporary residence within the State, of whatever duration, does not constitute domicile. Migrant workers who can document a previous history of work in New Jersey are eligible for consideration.

§ 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 for those children who have applied to the State Office.

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

(a) Upon receipt of the application from the local agency, the State Office shall consider the providers' and vendors' charges submitted.

(b) Providers shall be able to demonstrate licensure or certification by appropriate State or Federal agencies, if requested by 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 and make a decision on the Fund's level of assistance for each case. The calendar for the batch reviews shall be made available to the public by the State Office in advance of each year.

§ 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 Annual cap and vehicle allowance; home modification allowance; speech, language and hearing allowance; applied behavioral analysis allowance

- (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 of a lease or 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 allowance shall be capped at \$ 6,000 annually.

§ 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.

§ 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 exceed 10 percent of the first \$100,000 of annual income of a family plus 15 percent of the excess income over \$100,000;
 - 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. Consider the reasonableness of providers and vendor charges;

6. Prepare applications for review and consideration of the Commission; and
7. Oversee payments to providers, vendors and, in some cases, to families.

§ 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;
 2. Meet to review and make decisions on applications of families for financial assistance in regularly scheduled cycles; and
 3. Negotiate or settle the recovery of funds disbursed in accordance with the provisions of this chapter.

§ 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. The income will be reported for the same prior consecutive 12-month time period back to January 1988. In addition, a supplemental statement of income and expenses may be submitted at the request of the State Office. Applications shall be accepted any time throughout the year.

§ 10:155-1.14 Eligible health services

(a) Categories of incurred health expenses which are medically-authorized in the care of a child with an illness or condition eligible for consideration is assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$100,000 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 addiction disorders and mental health care, dental care, eye care, chiropractic care;
3. Care in an acute hospital in New Jersey (treatment for acute and chronic conditions and treatment of addiction disorders and mental health conditions);
4. Care in acute hospitals in other states (treatment for acute and chronic conditions, and treatment of addiction disorders and mental health conditions as well as highly specialized care such as organ transplants);
5. Physicians and nursing services in all settings, including primary care (preventive care) and immunization services (for example, office, hospital);
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 leased or specialized, modified vehicle and any subsequent modifications that are related to the medical condition of the child at the time the expenses were incurred; and

14. Experimental medical treatment/experimental drugs which are recognized by Federal or State agencies and provided by licensed health care providers. Applications involving experimental treatment/experimental drugs may require additional review.

(b) Categories of incurred health-related expenses are eligible for consideration in assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 include:

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

(c) Fifty percent of a health insurance 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) or (b) above.

§ 10:155-1.15 Ineligible health services

(a) Categories of health and health-related expenses which are not eligible for consideration in assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 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 Commission.

§ 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 received at 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. 52:14 B-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 cap 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.

Examples of Catastrophic Illness in Children Relief Fund Program*:

The examples below illustrate the extent to which the Fund would assist three families with different income levels.

FAMILY #1 (with income of \$ 30,000)

Family income:.....	\$ 30,000
Eligibility Standard (Exceeding 10% of income):	3,000
Amount of Eligible Medical Expenses not Covered by Insurance:.....	15,000
Family Responsibility (Exceeding 10% of Eligibility Standard):.....	300
Amount of Fund's Financial Assistance to Family:	14,700
Amount for which Family remains responsible:	300

FAMILY #2 (with income of \$ 80,000)

Family income:.....	\$80,000
Eligibility Standard (Exceeding 10% of income):	8,000
Amount of Eligible Medical Expenses not Covered by Insurance:.....	15,000
Family Responsibility (Exceeding 10% of Eligibility Standard):.....	800
Amount of Fund's Financial Assistance to Family:	14,200
Amount for which Family remains responsible:	800

FAMILY #3 (with income of \$ 120,000)

Family income:.....	\$ 120,000
Eligibility Standard:.....	13,000
Exceeding 10% of the first \$ 100,000 or 10,000	
Exceeding 15% of the excess over \$ 100,000 or 3,000	
Amount of Eligible Medical Expenses not Covered by Insurance:.....	15,000
Family Responsibility (Exceeding 10% of Eligibility Standard):.....	1,300
Amount of Fund's Financial Assistance to Family:	13,700
Amount for which Family remains responsible:	1,300

*Assuming: an annual \$ 100,000 cap; adequate monies available in Fund obviating need for additional restrictions and cost-sharing; and none of the cases are in the "special" category.