

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.

July 2010 - June 2011



Chris Christie, Governor

Kim Guadagno, Lieutenant Governor

Jennifer Velez, Commissioner of Human Services

Janice Pronnicki, CICRF Chairperson

Claudia L. Marchese, CICRF Executive Director



CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION

PUBLIC MEMBERS OF THE COMMISSION

Janice Pronnicki, M.D., M.P.H., F.A.A.P., Chairperson

Ellen DeRosa, Vice Chairperson

Virginia Hammer, R.N.

Howard Weinberg, D.O.

Carl Underland

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Paula A. Mullaly, Esq. (through December 2010)

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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, 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 2010 to June 2011.**

In State Fiscal Year 2011, the Catastrophic Illness in Children Relief Fund Commission approved approximately \$5.5 million in grant awards for 327 families. Since the first grant awards were approved in December 1989, approximately **\$136M has been awarded to over 5,700 families.**

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

With best wishes,

Janice Pronnicki

Janice Pronnicki, M.D., M.P.H., F.A.A.P.
Chairperson

EXECUTIVE SUMMARY

The Catastrophic Illness in Children Relief Fund Commission (The Fund) approved \$5.5M in grant awards for families in need during State Fiscal Year 2011 (SFY'11). 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, 2011, approximately \$136M has been awarded to New Jersey families.

The data on awards approved in SFY'11 demonstrates that financial help was available to meet the diverse needs of 327 New Jersey families with awards ranging from \$880 to \$100,000. The average award per family was \$16,880.37. Financial assistance from The Fund provided relief for costs associated with a wide array of medical problems, from simple fractures to rare genetic disorders.

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 out to 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.

The Commission's cost savings initiatives through regulatory caps and negotiations of discounts with providers yielded savings of approximately \$1.43M in SFY11. Since the inception of The Fund, the Commission has achieved over \$21M in total discounts. This effort continues a long-standing practice of the Commission to reduce costs, whenever possible, to ensure it can continue to help New Jersey families in need.

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

TABLE OF CONTENTS

Letter of Transmittal

Executive Summary

I. Background

II. Service Statistics

III. Policy Issues

IV. Appendices

A. *N.J.S.A. 26:2-148 et seq., The Catastrophic Illness in Children Relief Fund Act*

B. *N.J.A.C. 10:155, The Catastrophic Illness in Children Relief Fund Program*

ACKNOWLEDGEMENTS

The Catastrophic Illness in Children Relief Fund Commission (CICRF) would like to thank the NJ Department of Human Services for administrative support. The Commission also acknowledges the contributions of member designees in SFY'11, including:

- William A.B. Ditto of the NJ Department of Human Services (through December 2010)
- Joseph M. Amoroso of the NJ Department of Human Services (after December 2010)
- Pauline Lisciotto of the NJ Department of Health
- John Megariotis 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.

BACKGROUND

The Catastrophic Illness in Children Relief Fund (The Fund)

The Catastrophic Illness in Children Relief Fund was established by statute (P.L.1987 c.370) to provide financial assistance to families whose children have experienced an illness or condition not fully covered by insurance, state or federal program, or any other resource. The Fund is designed to provide a financial safety net for families struggling with a child's previously incurred medical expenses.

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 exceed the established eligibility threshold. In State Fiscal Year 2011 (SFY'11), 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 income over \$100,000.

"Child" includes someone 21 years of age and younger, so that The Fund can continue to provide continuity in financial assistance for the young adult population.

The family must be a resident of New Jersey for at least three months prior to submission of an application. Temporary residents, including individuals 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 during which the expenses were incurred. The Catastrophic Illness in Children Relief 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 subject to established caps and program regulations.

State Significance

The cost of coverage remains a significant obstacle for many families in New Jersey to access health insurance. For families with insurance who applied for assistance, their health coverage was inadequate for the medical needs of their child. For most families health insurance is tied to employment. Once a parent no longer has health coverage through a job, the family often is unable to afford the cost of health insurance premiums.

At the same time, the cost of health care is increasing, particularly for hospital, physician, and pharmacy services. Employers are increasingly passing on costs for employee and/or dependent coverage to employees in the form of larger premiums, higher deductibles and co-payments. The downgrading of benefits by employers continues to impact parents and children. Employers who offer self-funded health plans 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 so families with these plans may encounter health situations that fall outside the coverage, which still qualifies them for assistance from The Fund.

BACKGROUND

Although subsidized health coverage for uninsured children is available through NJ Family Care, 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 often pays for medical-related expenses that are not covered through NJ Family Care and other State programs.

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 vulnerable to personal and financial distress from catastrophic medical costs.

Catastrophic Illness in Children Relief Fund Commission

In January 2008, the Commission's statute was amended by P.L.2008 c. 342, establishing it in the Executive Branch of the New Jersey State government and allocating it within the New Jersey Department of Human Services (DHS). Notwithstanding that allocation, the Commission is 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'11, 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 this state. The ex officio members are the Commissioners of DHS, the NJ Department of Banking and Insurance, the NJ Department of Treasury, the Department of Health, and the Department of Children and Family.

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 confidential files on all applicant families. The Fund is operated within the intent and provisions of its statute, program regulations, and in compliance with Commission policies and decisions.

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

Coordination with Special Child, Adult and Early Intervention Services

The Fund works in collaboration with Special Child, Adult and Early Intervention Services (SCAEIS) in DOH. 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 that families have access to program information and referral at the local level.

Collection and Accounting of the Fund

In accordance with the provisions of *P.L.2008, C342*, 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 to the State Treasurer for deposit into The Fund. Interest earned on money collected is credited to The Fund.

BACKGROUND**CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND****Fund Balance**

	ACTUAL FY'10	ACTUAL FY'11
REVENUES:		
FUND BALANCE JULY 1	\$ 958,943	\$ 498,364
SERVICES AND ASSESSMENTS	\$ 7,980,027	\$ 8,045,294
INVESTMENT EARNINGS	\$ 7,467	\$ 2,903
CONTRIBUTION (DONATIONS)	\$ 135	\$ 0
TOTAL REVENUE	\$ 8,946,572	\$ 8,546,561
EXPENDITURES:		
DEPARTMENT OF HEALTH	\$ (107,927)	\$ (107,927)
FAMILIES AND PROVIDERS	\$ (6,856,933)	\$ (5,499,215)
OPERATING EXPENSES	\$ (1,483,348)	\$ (1,155,056)
TOTAL EXPENDITURES	\$ (8,448,208)	\$ (6,762,198)
FUND BALANCE JUNE 30	\$ 489,364	\$ 1,784,363

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'11, the Commission processed 526 applications. Of those applications, the Commission approved over \$5.5M for 327 families.

TOTAL AWARDS APPROVED	\$5.5M
TOTAL APPLICATIONS APPROVED	327
Range of Awards	\$880 - \$100,000
Average	\$16,880.37
Range of Income	\$0 - \$436,429
Average	\$51,129.08
Average Expense: Income	39.6%

The applications reviewed by the Commission reflected a range of uncovered expenses among families in need. Awards approved by the Commission in SFY'11 ranged from \$880 to \$100,000, with an average award of \$16,880.37.

SERVICE STATISTICS - SFY '11**Table 1****CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION
APPLICATIONS BY COUNTY SFY '11**

COUNTY	TOTAL REVIEWED	ELIGIBLE	INELIGIBLE	TOTAL EXPENSES	EXPENSES WITH CAPS	EXPENSES WITH CAPS & DISCOUNTS
ATLANTIC	12	4	8	\$72,929.00	\$59,978.62	\$59,978.62
BERGEN	54	30	24	\$1,150,738.48	\$1,056,061.33	\$878,732.58
BURLINGTON	29	13	16	\$419,841.30	\$318,100.22	\$312,953.32
CAMDEN	28	19	9	\$296,131.13	\$287,993.38	\$284,377.44
CAPE MAY	4	2	2	\$64,673.09	\$61,002.09	\$61,002.09
CUMBERLAND	3	1	2	\$15,865.00	\$15,865.00	\$15,865.00
ESSEX	19	9	10	\$282,640.24	\$194,745.35	\$189,226.35
GLOUCESTER	9	4	5	\$221,808.07	\$152,231.42	\$151,237.00
HUDSON	22	11	11	\$318,314.82	\$285,467.24	\$264,970.74
HUNTERDON	5	3	2	\$39,374.63	\$32,782.00	\$32,782.00
MERCER	18	11	7	\$256,672.92	\$217,171.14	\$216,672.84
MIDDLESEX	30	17	13	\$472,881.36	\$409,293.98	\$390,264.76
MONMOUTH	26	13	13	\$359,122.79	\$287,591.40	\$287,527.40
MORRIS	31	21	10	\$688,108.37	\$433,551.42	\$410,828.74
OCEAN	152	124	28	\$1,227,934.88	\$1,118,110.70	\$1,090,146.16
PASSAIC	28	18	10	\$379,515.30	\$335,321.22	\$327,139.33
SALEM	2	1	1	\$13,915.00	\$13,915.00	\$13,915.00
SOMERSET	10	5	5	\$217,495.67	\$150,091.67	\$150,091.67
SUSSEX	16	9	7	\$131,041.00	\$119,955.67	\$116,500.67
UNION	24	11	13	\$283,026.65	\$245,004.68	\$229,855.18
WARREN	4	1	3	\$21,122.11	\$15,148.11	\$15,148.11
TOTALS	526	327	199	\$6,933,151.81	\$5,809,381.64	\$5,499,215.00

*Utilization of regulatory caps combined with standardized discounts saved The Fund approximately \$1.43M in SFY'11.

SERVICE STATISTICS - SFY '11

Review of Categories of 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 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 elective cosmetic surgery or special education services required as a result of a medical condition.

Chapter 10:155 identifies the categories of health services that are considered to be eligible and 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'11.

Category of Eligible Health Service	Average	Category of Eligible Health Service	Average
Transportation	26%	Pharmacy	2%
Hospital, In-State	13%	Funeral Expenses	1%
Physician Services	13%	Disposable Medical Supplies	<1%
Specialty Pediatric Ambulatory Care	13%	Ancillary Services	<1%
Specialty Hospital, Out-of State	8%	Home Health Care	<1%
Home Modification	8%	Temporary Shelter	<1%
Health Insurance	6%	Telephone	<1%
Hospital, Out-of-State	3%	Specialty Hospital, In-State	<1%
Durable Medical Equipment	2%	Experimental Services	0
Long Term Care	2%		

SERVICE STATISTICS - SFY '11

Review of Medical Conditions

Families apply to the Catastrophic Illness in Children Relief Fund for their children's already incurred 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'11. 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'10 Eligible Applications	
Code	Diagnosis (N=300)
155.0	Malignant Neoplasm Of Liver, Primary
170.9	Malignant Neoplasm Of Bone And Articular Cartilage, Site Unspecified
189.0	Malignant Neoplasm Of Kidney, Except Pelvis
191	Malignant Neoplasm Of Brain
191.6	Malignant Neoplasm Of Cerebellum NOS
192.2	Malignant Neoplasm Of Spinal Cord
199.1	Other Malignant Neoplasm Of Unspecified Site
201.	Hodgkin's Disease
202.80	Other Malignant Lymphomas, Unspecified Site, Extranodal And Solid Organ Sites
204	Lymphoid Leukemia
204.0	Acute Lymphoid Leukemia
204.00	Acute Lymphoid Leukemia, Without Mention Of Having Achieved Remission
205.0	Acute Myeloid Leukemia
225.0	Benign Neoplasm Of Brain
228.01	Hemangioma Of Skin And Subcutaneous Tissue
238.7	Other Lymphatic And Hematopoietic Tissues
239.1	Neoplasm Of Unspecified Nature Of Respiratory System
239.6	Neoplasm Of Unspecified Nature Of Brain
250	Diabetes Mellitus

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
250.01	Diabetes Mellitus Without Mention Of Complication, Type I [Juvenile Type], Not Stated As Uncontrolled
250.13	Diabetes With Ketoacidosis, Type I [Juvenile Type], Uncontrolled
253.3	Pituitary Dwarfism
253.5	Diabetes Insipidus
259.4	Dwarfism, Not Elsewhere Classified
266.2	Other B-Complex Deficiencies
270.1	Phenylketonuria (PKU)
270.2	Other Disturbances Of Aromatic Amino-Acid Metabolism
270.4	Disturbances Of Sulphur-Bearing Amino-Acid Metabolism
270.6	Disorders Of Urea Cycle Metabolism
276.1	Hyposmolality And/Or Hyponatremia
277.5	Mucopolysaccharidosis
277.87	Disorders Of Mitochondrial Metabolism
279.3	Unspecified Immunity Deficiency
284.9	Unspecified Aplastic Anemia
293.83	Mood Disorder In Conditions Classified Elsewhere
293.84	Anxiety Disorder In Conditions Classified Elsewhere
295.70	Schizoaffective Disorder, Unspecified
296.22	Major Depressive Disorder, Single Episode, Moderate
296.23	Major Depressive Disorder, Single Episode, Severe, Without Mention Of Psychotic Behavior
296.3	Major Depressive Disorder, Recurrent Episode
296.32	Major Depressive Disorder, Recurrent Episode, Moderate
296.80	Bipolar Disorder, Unspecified
296.90	Unspecified Episodic Mood Disorder
299	Pervasive Developmental Disorders
299.0	Autistic Disorder
299.00	Autistic Disorder, Current Or Active State
299.8	Other Specified Pervasive Developmental Disorders
299.9	Unspecified Pervasive Developmental Disorder
299.90	Unspecified Pervasive Developmental Disorder, Current Or Active State
300.00	Anxiety State, Unspecified
300.02	Generalized Anxiety Disorder
300.2	Phobic Disorders
301.83	Borderline Personality Disorder
301.9	Unspecified Personality Disorder
303.90	Other And Unspecified Alcohol Dependence, Unspecified Drunkenness
304.30	Cannabis Dependence, Unspecified Abuse
304.80	Combinations Of Drug Dependence Excluding Opioid Type Drug, Unspecified Abuse
305.20	Nondependent Cannabis Abuse, Unspecified
307.23	Tourette's Disorder
307.5	Other And Unspecified Disorders Of Eating
307.51	Bulimia Nervosa
307.9	Other And Unspecified Special Symptom Or Syndrome, Not Elsewhere Classified
309.0	Adjustment Disorder With Depressed Mood
309.24	Adjustment Disorder With Anxiety

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
309.4	Adjustment Disorder With Mixed Disturbance Of Emotions And Conduct
309.81	Post-traumatic Stress Disorder (PTSD)
309.9	Unspecified Adjustment Reaction
311	Depressive Disorder, Not Elsewhere Classified
312.89	Other Specified Disturbance Of Conduct, Not Elsewhere Classified
313.81	Oppositional Defiant Disorder
313.89	Other Emotional Disturbance Of Childhood Or Adolescence
314	Hyperkinetic Syndrome Of Childhood
314.0	Attention Deficit Disorder Of Childhood
314.01	Attention Deficit Disorder Of Childhood With Hyperactivity
315.31	Expressive Language Disorder
315.32	Mixed Receptive-Expressive Language Disorder
315.39	Other Developmental Speech Or Language Disorder
315.9	Unspecified Delay In Development
317	Mild Mental Retardation
318.1	Severe Mental Retardation
318.2	Profound Mental Retardation
327.21	Primary Central Sleep Apnea
330.0	Leukodystrophy
330.1	Cerebral Lipidoses
330.8	Other Specified Cerebral Degenerations In Childhood
331.4	Obstructive Hydrocephalus
331.5	Idiopathic Normal Pressure Hydrocephalus [INPH]
333.89	Other Fragments Of Torsion Dystonia
334.8	Other Spinocerebellar Diseases
335.0	Werdnig-Hoffmann Disease
335.1	Spinal Muscular Atrophy
335.10	Unspecified Spinal Muscular Atrophy
343	Infantile Cerebral Palsy
343.0	Diplegic Infantile Cerebral Palsy
343.2	Quadriplegic Infantile Cerebral Palsy
343.9	Unspecified Infantile Cerebral Palsy
344.1	Paraplegia
345.	Epilepsy And Recurrent Seizures
345.0	Generalized Nonconvulsive Epilepsy
345.1	Generalized Convulsive Epilepsy
345.11	Generalized Convulsive Epilepsy With Intractable Epilepsy
345.40	Localization-Related (Focal) (Partial) Epilepsy And Epileptic Syndromes With Complex Partial Seizures, Without Mention Of Intractable Epilepsy
345.9	Unspecified Epilepsy
346.1	Migraine Without Aura
346.91	Migraine, Unspecified With Intractable Migraine, So Stated, Without Mention Of Status Migrainosus
348.0	Cerebral Cysts
348.1	Anoxic Brain Damage
348.3	Encephalopathy, Not Elsewhere Classified

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
348.30	Encephalopathy, Unspecified
359.1	Hereditary Progressive Muscular Dystrophy
359.8	Other Myopathies
359.9	Unspecified Myopathy
365	Glaucoma
367.1	Myopia
369.00	Blindness Of Both Eyes, Impairment Level Not Further Specified
369.9	Unspecified Visual Loss
370.35	Neurotrophic Keratoconjunctivitis
370.63	Deep Vascularization Of Cornea
371	Corneal Opacity And Other Disorders Of Cornea
375.22	Epiphora Due To Insufficient Drainage
377.75	Disorders Of Visual Cortex Associated With Cortical Blindness
378.8	Other Disorders Of Binocular Eye Movements
378.83	Convergence Insufficiency Or Palsy In Binocular Eye Movement
378.9	Unspecified Disorder Of Eye Movements
379.07	Posterior Scleritis
379.50	Unspecified Nystagmus
379.57	Nystagmus With Deficiencies Of Saccadic Eye Movements
379.58	Nystagmus With Deficiencies Of Smooth Pursuit Movements
382.9	Unspecified Otitis Media
388.45	Acquired Auditory Processing Disorder
389.06	Conductive Hearing Loss, Bilateral
389.10	Unspecified Sensorineural Hearing Loss
389.12	Neural Hearing Loss, Bilateral
389.9	Unspecified Hearing Loss
403.9	Hypertensive Chronic Kidney Disease, Unspecified
424.0	Mitral Valve Disorders
424.3	Pulmonary Valve Disorders
432.9	Unspecified Intracranial Hemorrhage
448.1	Nevus, Non-Neoplastic
453.9	Embolism And Thrombosis Of Unspecified Site
474.01	Chronic Adenoiditis
474.12	Hypertrophy Of Adenoids Alone
477	Allergic rhinitis
478.30	Unspecified Paralysis Of Vocal Cords Or Larynx
493.	Asthma
493.0	Extrinsic Asthma
493.00	Extrinsic Asthma, Unspecified
493.02	Extrinsic Asthma, With (Acute) Exacerbation
496	Chronic Airway Obstruction, Not Elsewhere Classified
518.3	Pulmonary Eosinophilia
520.6	Disturbances In Tooth Eruption
521.8	Other Specific Diseases Of Hard Tissues Of Teeth
522	Diseases Of Pulp And Periapical Tissues

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
524	Dentofacial Anomalies, Including Malocclusion
524.04	Mandibular Hypoplasia
524.22	Malocclusion, Angles Class II
524.23	Malocclusion, Angles Class III
524.24	Anomaly Of Dental Arch Relationship, Open Anterior Occlusal Relationship
524.31	Crowding Of Teeth
524.4	Unspecified Malocclusion
524.60	Unspecified Temporomandibular Joint Disorders
524.64	Temporomandibular Joint Sounds On Opening And/Or Closing The Jaw
524.7	Dental Alveolar Anomalies
528.9	Other And Unspecified Diseases Of The Oral Soft Tissues
530.11	Reflux Esophagitis
530.13	Eosinophilic Esophagitis
530.19	Other Esophagitis
530.8	Other Specified Disorders Of Esophagus
530.81	Esophageal Reflux
530.85	Barrett's Esophagus
540.9	Acute Appendicitis Without Mention Of Peritonitis
550.90	Inguinal Hernia Without Mention Of Obstruction Or Gangrene, Unilateral Or Unspecified, (Not Specified As Recurrent)
555.0	Regional Enteritis Of Small Intestine
556	Ulcerative Colitis
556.9	Unspecified Ulcerative Colitis
558.3	Gastroenteritis And Colitis, Allergic
558.41	Eosinophilic Gastroenteritis
558.9	Other And Unspecified Noninfectious Gastroenteritis And Colitis
564.0	Constipation
575.10	Cholecystitis, Unspecified
579	Intestinal Malabsorption
591	Hydronephrosis
692	Contact Dermatitis And Other Eczema
692.9	Contact Dermatitis And Other Eczema, Due To Unspecified Cause
707.03	Pressure Ulcer, Lower Back
709.2	Scar Condition And Fibrosis Of Skin
714.30	Polyarticular Juvenile Rheumatoid Arthritis, Chronic Or Unspecified
719.49	Pain In Joint, Multiple Sites
723.5	Torticollis, Unspecified
727.81	Contracture Of Tendon (Sheath)
728.2	Muscular Wasting And Disuse Atrophy, Not Elsewhere Classified
728.3	Other Specific Muscle Disorders
728.87	Muscle Weakness (Generalized)
728.9	Unspecified Disorder Of Muscle, Ligament, And Fascia
729.1	Unspecified Myalgia And Myositis
737.30	Scoliosis (And Kyphoscoliosis), Idiopathic
737.39	Other Kyphoscoliosis And Scoliosis

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
737.43	Scoliosis Associated With Other Condition
741	Spina Bifida
741.0	Spina Bifida With Hydrocephalus
741.9	Spina Bifida Without Mention Of Hydrocephalus
742.1	Microcephalus
742.2	Congenital Reduction Deformities Of Brain
742.3	Congenital Hydrocephalus
742.4	Other Specified Congenital Anomalies Of Brain
742.8	Other Specified Congenital Anomalies Of Nervous System
742.88	Cerebral Dysgenesis
742.9	Unspecified Congenital Anomaly Of Brain, Spinal Cord, And Nervous System
743.2	Buphthalmos
743.30	Unspecified Congenital Cataract
745.11	Transposition Of Great Vessels, Double Outlet Right Ventricle
745.4	Ventricular Septal Defect
745.5	Ostium Secundum Type Atrial Septal Defect
746.1	Congenital Tricuspid Atresia And Stenosis
746.02	Congenital Stenosis Of Pulmonary Valve
746.4	Congenital Insufficiency Of Aortic Valve
746.7	Hypoplastic Left Heart Syndrome
746.87	Congenital Malposition Of Heart And Cardiac Apex
746.9	Unspecified Congenital Anomaly Of Heart
747.0	Patent Ductus Arteriosus
747.10	Coarctation Of Aorta (Preductal) (Postductal)
748.3	Other Congenital Anomaly Of Larynx, Trachea, And Bronchus
749.21	Unilateral Cleft Palate With Cleft Lip, Complete
750.0	Tongue Tie
750.3	Congenital Tracheoesophageal Fistula, Esophageal Atresia And Stenosis
750.7	Pyloric Stenosis
751	Other Congenital Anomalies Of Digestive System
751.2	Congenital Atresia And Stenosis Of Large Intestine, Rectum, And Anal Canal
751.3	Hirschsprung's Disease And Other Congenital Functional Disorders Of Colon
752.51	Undescended Testis
753.29	Other Obstructive Defect Of Renal Pelvis And Ureter
754.81	Pectus Excavatum
755.31	Congenital Transverse Deficiency Of Lower Limb
756	Other Congenital Musculoskeletal Anomalies
756.0	Congenital Anomalies Of Skull And Face Bones
756.79	Other Congenital Anomalies Of Abdominal Wall
757.39	Other Specified Congenital Anomaly Of Skin
758	Chromosomal Anomalies
758.2	Edwards' Syndrome
758.89	Other Conditions Due To Chromosome Anomalies
758.9	Conditions Due To Anomaly Of Unspecified Chromosome
759	Other And Unspecified Congenital Anomalies

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
759.5	Tuberous Sclerosis
759.7	Multiple Congenital Anomalies, So Described
759.81	Prader-Willi Syndrome
759.89	Other Specified Multiple Congenital Anomalies, So Described
763.4	Fetus Or Newborn Affected By Cesarean Delivery
765.03	Extreme Fetal Immaturity, 750-999 Grams
765.04	Extreme Fetal Immaturity, 1,000-1,249 Grams
765.10	Other Preterm Infants, Unspecified (Weight)
765.14	Other Preterm Infants, 1,000-1,249 Grams
765.16	Other Preterm Infants, 1,500-1,749 Grams
765.25	29-30 Completed Weeks Of Gestation
765.26	31-32 Completed Weeks Of Gestation
765.28	35-36 Completed Weeks Of Gestation
768.5	Severe Birth Asphyxia
768.70	Hypoxic-Ischemic Encephalopathy, Unspecified
769	Respiratory Distress Syndrome In Newborn
770.12	Meconium Aspiration With Respiratory Symptoms, Of Fetus And Newborn
770.81	Primary Apnea Of Newborn
771.1	Congenital Cytomegalovirus Infection
771.81	Septicemia (Sepsis) Of Newborn
774.2	Neonatal Jaundice Associated With Preterm Delivery
775.6	Neonatal Hypoglycemia
778.3	Other Hypothermia Of Newborn
779.34	Failure To Thrive In Newborn
779.7	Periventricular Leukomalacia
780.3	Convulsions
780.39	Other Convulsions
780.53	Hypersomnia With Sleep Apnea, Unspecified
780.57	Unspecified Sleep Apnea
781.0	Abnormal Involuntary Movements
781.3	Lack Of Coordination
781.9	Other Symptoms Involving Nervous And Musculoskeletal Systems
782.1	Rash And Other Nonspecific Skin Eruption
783.0	Anorexia
783.21	Loss Of Weight
783.3	Feeding Difficulties And Mismanagement
783.4	Lack Of Expected Normal Physiological Development
783.40	Lack Of Normal Physiological Development, Unspecified
783.41	Failure To Thrive
783.42	Delayed Milestones
784.2	Swelling, Mass, Or Lump In Head And Neck
784.49	Other Voice And Resonance Disorders

SERVICE STATISTICS - SFY '11

Code	Diagnosis (N=300)
784.60	Symbolic Dysfunction, Unspecified
784.69	Other Symbolic Dysfunction
785.2	Undiagnosed Cardiac Murmurs
786.09	Other Dyspnea And Respiratory Abnormalities
787.2	Dysphagia
787.20	Dysphagia, Unspecified
787.6	Incontinence Of Feces
806.9	Open Fracture Of Unspecified Vertebra With Spinal Cord Injury
814.01	Closed Fracture Of Navicular (Scaphoid) Bone Of Wrist
854	Intracranial Injury Of Other And Unspecified Nature
873.44	Open Wound Of Jaw, Without Mention Of Complication
883.1	Open Wound Of Finger(s), Complicated
959.1	Injury, Other And Unspecified, Trunk
977.9	Poisoning By Unspecified Drug Or Medicinal Substance
995.0	Other Anaphylactic Shock Not Elsewhere Classified
995.60	Anaphylactic Shock Due To Unspecified Food

Legislative and Regulatory Changes

In November 2010 Governor Chris Christie signed amending legislation that directed the Commission to waive the family responsibility for any additional children for which a family applies for assistance, in the event the family has to pay the family responsibility for the first child in a state fiscal year. This legislation codified the policy that was already in use by the State Office staff. Under Commission regulations (N.J.A.C. 10:155-1.2), family responsibility is defined as the amount equal to 10% of the eligibility standard; and the eligibility standard is defined as the dollar amount equal to 10% of the first \$100,000 of annual income of a family plus 15% of the excess income of \$100,000. The legislative amendment ensures that once a family with more than one child with a catastrophic illness has a family responsibility imposed for the first child, the family will not have to pay a family responsibility for any additional children in the same fiscal year.

Also during the fiscal year, regulatory changes were made to consider fifty percent of the cost of a health coverage premium paid by the family (including supplemental and dependent coverage) when that cost is accompanied by other eligible expenses. The premium now is considered toward calculating eligibility only, and is not an eligible expense for reimbursement. However, the amount of the health coverage premium considered is not to exceed 50 percent of the eligible expenses. In the event that 50 percent of the premium exceeds 50 percent of the eligible expenses a special formula is used to determine eligibility. Previously, fifty percent of the health insurance premium paid by the family was considered as both an eligible expense for reimbursement and was included when determining eligibility. This regulatory change enables families to continue to be eligible for assistance through the program, while preserving resources for all New Jersey families.



POLICY ISSUES

Fiscal Issues

The Commission continued prudent fiscal practices in SFY'11 that preserved resources for families applying for financial assistance. In addition to implementing various regulatory caps, staff continued the practice of successfully negotiating discounts with outstanding providers. All families were held harmless from any of these balances. Implementation of these regulatory and non-regulatory provisions realized savings of approximately \$1.38M in SFY'11. Since the discount policy was adopted in 1994, the Commission realized savings of over \$24M.

Public Information

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. In SFY'11, 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 unique 800-phone number continued to be available for the public as the Family Information Line, 1-800-335-FUND. The Fund's website also is available for the public, www.njcatastrophicfund.org.

The Fund continued to present to groups not familiar with the Fund or to those who are in contact with families. The Fund also exhibits at conferences and conventions. The practice of following up with community organizations, schools, individual families and small groups representing parents of children with disabilities continued and when possible presentations to these groups were made.

The Commission's Annual Meeting was held on June 29, 2011, where the Commission joined members of the Family Advisory Committee (FAC) and guests. The meeting was held in the Masonic Temple and honored guests included Commission Members, staff, and many families and applicant children. FAC supports the Commission in disseminating program information on the local level. In SFY'11, the FAC had 133 families.

The Fund has seen a significant increase in the number of requested and received applications. Program information requests were generated from a variety of sources, including but not limited to health care providers, schools, special children's programs, and other State programs. Special Child Health Services also has been instrumental in referring many families to the program. In addition, The Fund continues to receive requests for information through the 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 also can be accessed through the 211 information and referral system, and through web links at various organizations and companies, including but not limited to Virtua Health Systems, Parent Partners Muscular Dystrophy, the ARC, Family Support Center of NJ 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 League of Municipalities, American Academy of Pediatrics, NJ Association of Counties, National Caregivers, Women in Municipal Government, 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 identified through our newspaper clipping service and to reporters who have written stories on ill children.

POLICY ISSUES

In the past, many of the applications received from families were initiated by health providers. It was decided that The Fund would expand outreach efforts in an attempt to connect with 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.

Testimonials

Families from all socio-economic backgrounds applied for assistance and expressed their gratitude for the financial support they received. The following testimonials from recipient families validate the success and effectiveness of the Catastrophic Illness in Children Relief Fund Program:

Thank you for taking the time to work with me and help my family through a difficult time. The relief provided by the Fund has proved to be a great help easing the burden of my son's illness.

(Flanders, Morris County parents of a 4-year-old)

Just wanted to say thank you for all your help. You have been so patient and helpful in many ways, answering our questions and keeping us up to date. Your help has been appreciated. There aren't that many people in this world that hold your hand when you're down. We thank everyone at the Catastrophic Illness in Children Relief Fund program. Help came when we needed it the most.

(Boonton, Morris County parents of a 21-year-old)

We cannot thank you enough for helping our family. We want you to know that this program is essential and that your hard work is really making a difference. Our son will now be able to continue with his therapies which will help him progress and overcome some of his challenges. Our family hopes that this program will continue and that you all will be commended for your dedication. Thank you again and again!

(Palmyra, Burlington County parents of a 5-year-old)

Thank you to the Catastrophic Illness in Children Relief Fund, the Commission and staff for helping our family with the challenge of having a child with a disability. It means a lot to our family.

(Cranford, Union County parents of a 21-year-old)

Thank you so much for your generous assistance. It truly is a blessing for us.

(Pine Brook, Morris County parents of a 2-year-old)

Thank you to the Catastrophic Illness in Children Relief Fund Commission for your generous assistance with our son. The assistance with the medical co-pays and modifications to our home has made it considerably more accessible and independent for our son with his on-going recovery. Thank you again for all your consideration.

(Elmer, Salem County parents of a 19-year-old)

POLICY ISSUES

Conclusion

Any family in New Jersey may find needed financial assistance from the Catastrophic Illness in Children Relief Fund if their child's uncovered medical expenses are disproportionate to their earnings. 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.

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 New Jersey families.

The public needs program information to be available directly as well as through traditional sources such as health care providers, state and community organizations. The Commission's Public Information Plan in SFY'11 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 promoting The Fund to its expanding population.

APPENDIX A

Enabling Legislation

§ 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.

APPENDIX A

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

The “Catastrophic Illness in Children Relief Fund” is established as a non-lapsing, 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 not withstanding 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.

APPENDIX A

§ 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

APPENDIX A

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 non competitive 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. 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, § 8; amended 1998, c. 143, § 4, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998. Amended P.L. 2010 c.84 eff. Dec. 3, 2010.

APPENDIX A

§ 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.

APPENDIX B

Regulations

§ 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, 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 source, which allows funds to provide for the medically related needs of a child, as defined in N.J.A.C. 10:155-1.14 including, but limited to, insurance contracts, trusts, proceeds from fundraising or settlements 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.

APPENDIX B

“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 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 prescriptions.

“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, 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.

APPENDIX B

“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” 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.

“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

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 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 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.

APPENDIX B

§ 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 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. 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 \$ 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 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.

IV.

Catastrophic Illness in Children Relief Fund Commission

APPENDIX B**§ 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. 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, to 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;
2. Meet to review and make decisions on applications of families for financial assistance in regularly scheduled cycles.

§ 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. Applications shall be accepted any time throughout the year.

§ 10:155-1.14 Eligible health services

(a) Categories of incurred health 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 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:

APPENDIX B

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;
 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, temporary shelter costs and telephone calls related to 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.

APPENDIX B

§ 10:155-1.15 Ineligible health services

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. 52:14 B-1 et seq., and the Uniform Administrative Procedure Rules, N.J.A.C. 1:1.

APPENDIX B

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.

APPENDIX B**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.



Catastrophic Illness in Children Relief Fund

Chris Christie, Governor

Kim Guadagno, Lieutenant Governor

Jennifer Velez, Commissioner of Human Services

Janice Pronnicki, CICRF Chairperson

Claudia L. Marchese, CICRF Executive Director