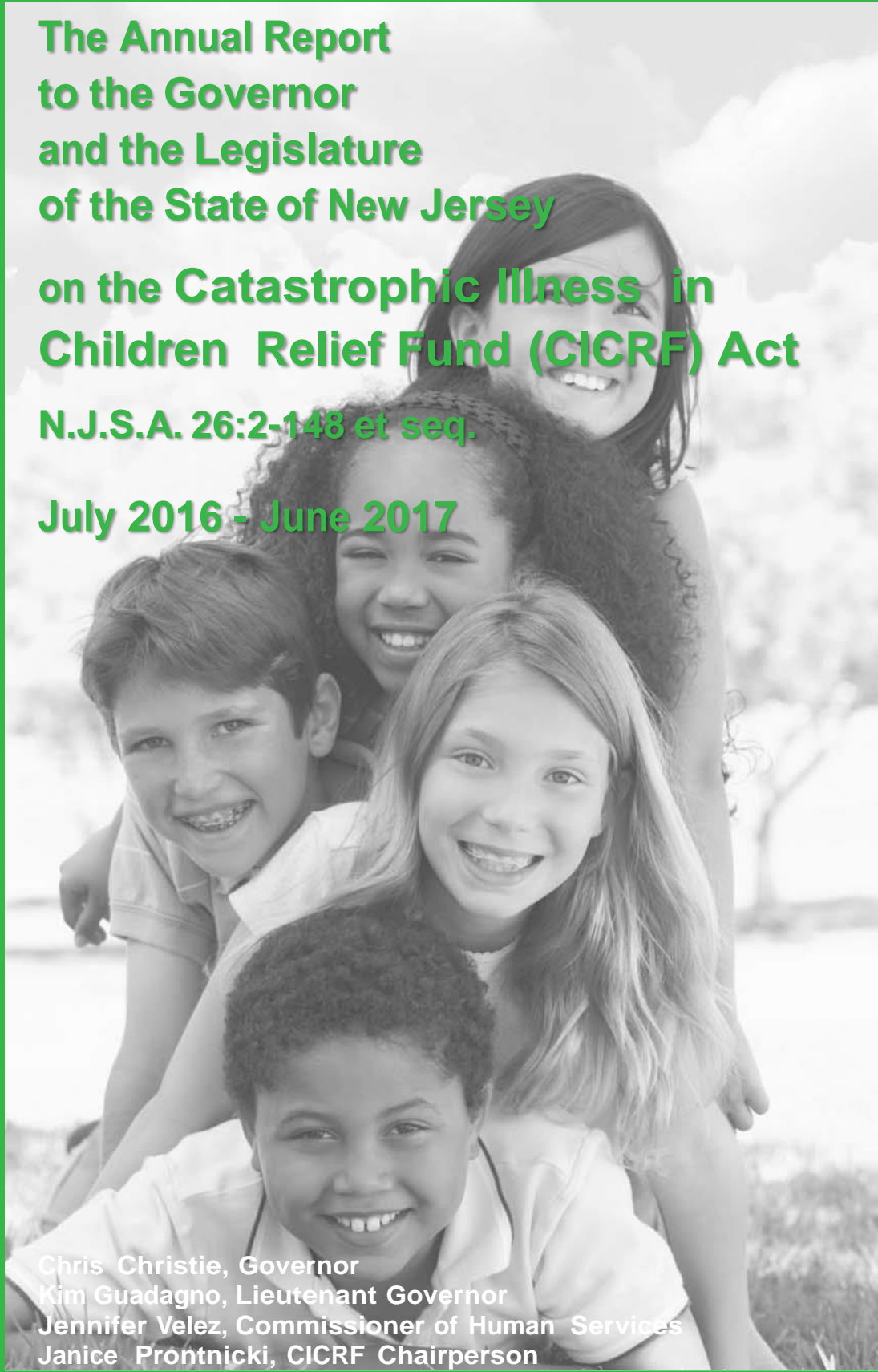


**The Annual Report
to the Governor
and the Legislature
of the State of New Jersey**

**on the Catastrophic Illness in
Children Relief Fund (CICRF) Act**

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

July 2016 - June 2017



**Chris Christie, Governor
Kim Guadagno, Lieutenant Governor
Jennifer Velez, Commissioner of Human Services
Janice Pronnicki, CICRF Chairperson**





MEMORANDUM

FROM: Christian Heiss, Executive Director

DATE: August 14, 2019

SUBJECT: Preparation of State Fiscal Year 2013-2017 Annual Reports to the Governor and Legislature

This memorandum is to describe the process used to finalize the annual reports to the Governor and Legislature of New Jersey on the status of the Catastrophic Illness in Children Relief Fund, as required by N.J.S.A. 26:2-159, for State Fiscal Years 2013 through 2017, covering the period of July 1, 2012 through June 30, 2017.

During the period described above, draft reports were prepared by staff of the State Office of the Fund. These reports were not finalized and therefore were not transmitted to the Governor and Legislature in a timely manner.

Upon my appointment in April 2019, I reviewed these 5 years of reports and conducted light copyediting, but did not materially change the content of the draft reports as I received them. At their August 2019 meeting the Commission voted to approve and issue the annual reports from State Fiscal Years 2013 through 2017, with a few additional copy and name edits, with inclusion of this memorandum in each report.

CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION

PUBLIC MEMBERS OF THE COMMISSION

Janice Pronnicki, M.D., M.P.H., F.A.A.P., Chairperson
Howard Weinberg, D.O.
Carl Underland
Ralph J. Condo
Phyllis Shanley Hansell

Jennifer Velez, Commissioner of Human Services
Allison Blake, Commissioner of Children and Families
Mary O'Dowd, Commissioner of Health
Andrew P. Sidamon-Eristoff, State Treasurer
Richard J. Badolato, Commissioner of Banking and Insurance

EXECUTIVE DIRECTOR

Claudia L. Marchese, Esq.

P.O. BOX 728, Trenton, NJ 08625-0728 • 609-292-0600
WWW.NJCATASTROPHICFUND.ORG



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

Dear Governor Christie:

Please see the enclosed 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 2016 to June 2017.

In State Fiscal Year 2017, the Catastrophic Illness in Children Relief Fund Commission approved nearly \$7 million in grant awards for 345 families. Since the first grant awards were approved in December 1989, approximately \$176 million has been awarded to over 8,404 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 that families do not have to bear the high out-of-pocket costs of their children's care alone.

With best wishes,

Janice Prontnicki

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

EXECUTIVE SUMMARY

The Catastrophic Illness in Children Relief Fund Commission (The Fund) approved nearly \$7 million in grant awards for families in need during State Fiscal Year 2017 (SFY'17). The Commission has been providing meaningful financial relief for New Jersey families since grant awards first were approved in December 1989. As of June 30, 2017, approximately \$176 million has been awarded to New Jersey families.

The data on awards approved in SFY'17 demonstrates that financial help was available to meet the diverse needs of 345 New Jersey eligible families with awards ranging from \$386 to \$82,465.94. The average award per family was \$17,266.00. 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, schools, hospitals, 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 nearly \$1 million in SFY'17. Since the inception of the Fund, the Commission has achieved nearly \$33 million 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.

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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'17, including:

- Riva Thomas of the NJ Department of Human Services
- Pauline Lisciotta of the NJ Department of Health
- John Megariotis of the NJ Department of Treasury
- Ellen DeRosa of the NJ Department of Banking and Insurance
- Latesha Holmes, of the NJ Department of Children and Families

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 this State Fiscal Year, 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 legal permanent residents 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.

The Catastrophic Illness in Children Relief Fund is unique in that it reviews expenses on a retrospective 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

Although health coverage for uninsured children in low income families is available through NJ Family Care, the state and federally-funded Medicaid and Children's Health Insurance (CHIP) Program, some families may experience a lapse in coverage during which a child may have uncovered medical expenses. In addition, the Fund often pays for medical condition-related expenses that are not covered through NJ Family Care and other State programs, such as home modifications for accessibility and modified vehicles.

Since its inception in 1989, the Commission has provided 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.

BACKGROUND

Catastrophic Illness in Children Relief Fund Commission

In January 2008, the Commission's statute was amended by P.L.2007 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) for administrative purposes. Notwithstanding that allocation, the Commission is independent from any supervision or control by the Department or by any board or officer thereof.

In SFY'17, 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 are providers of healthcare services for children in this state. The ex officio members are the Commissioners of DHS, the Department of Banking and Insurance, the Department of Treasury, the Department of Health, and the Department of Children and Families.

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 submit provider bills to insurance, seek Charity Care determinations, or otherwise utilize available resources before submitting an application for financial assistance. Staff also 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 the Department of Health. 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.2007 c.342*, the Commission is responsible for assessing a \$1.50 annual surcharge is collected per employee for all employers subject to the New Jersey Unemployment Compensation Law, *R.S.43:31-1 et seq* and deposited in a non-lapsing, revolving trust fund, used to pay for all CICRF operations and payments to providers and families. 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

	FY'16	Actual FY'17
REVENUES:		
FUND BALANCE JULY 1	\$2,615,233	\$3,592,436
SERVICES AND ASSESSMENTS	\$9,091,062	\$9,218,332
INVESTMENT EARNINGS	\$2,914	\$15,952
CONTRIBUTION (DONATIONS)	\$0	\$0
TOTAL REVENUE	\$9,093,976	\$9,234,284
EXPENDITURES:		
DEPARTMENT OF HEALTH	\$103,811	\$94,968
FAMILIES AND PROVIDERS	\$6,719,068	\$6,380,879
OPERATING EXPENSES	\$1,293,894	\$1,445,639
TOTAL EXPENDITURES	\$8,116,773	\$7,921,486
FUND BALANCE JUNE 30	\$3,592,436	\$4,905,234

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'17, the state office received 670 applications and processed 566 applications, with the inclusion of reconsiderations, ineligible and appeals. Of those applications, the Commission approved nearly \$7M for 345 eligible applications.

TOTAL AWARDS APPROVED	\$6,380,879.00
TOTAL APPLICATIONS APPROVED	345

Range of Awards	\$386.10 - \$100,000.00
Average	\$17,266.00

Range of Income	\$0 - \$623,620.00
Average	\$67,795.23

BACKGROUND

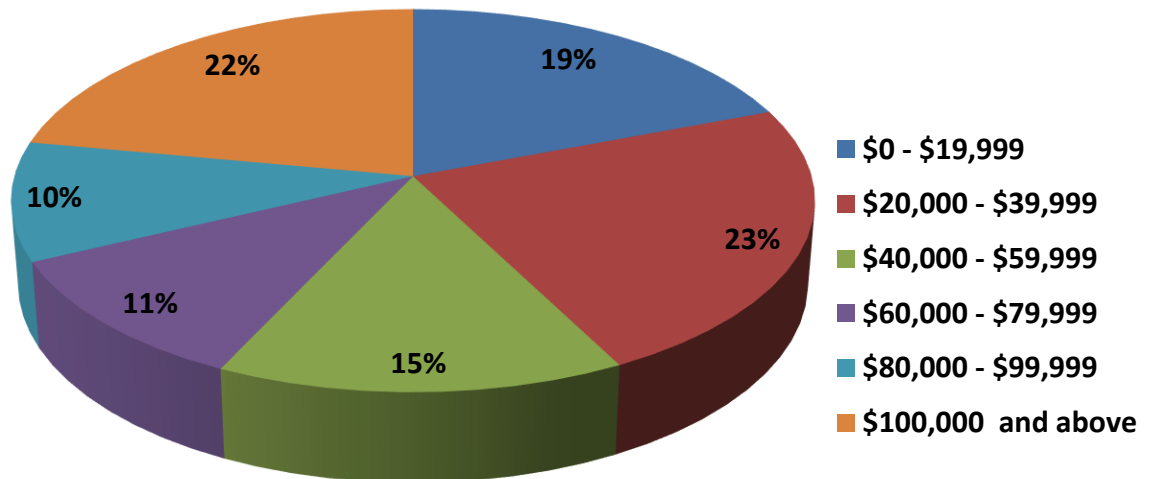
Average Expense: Income

64.4%

The applications reviewed by the Commission reflected a range of uncovered expenses among families in need. Awards approved by the Commission in SFY'17 ranged from \$386.00 to \$82,465.94 with an average award of \$17,266.00

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)

Application distribution by Income Level



SERVICE STATISTICS - SFY '17

CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION APPLICATIONS BY COUNTY SFY' 17

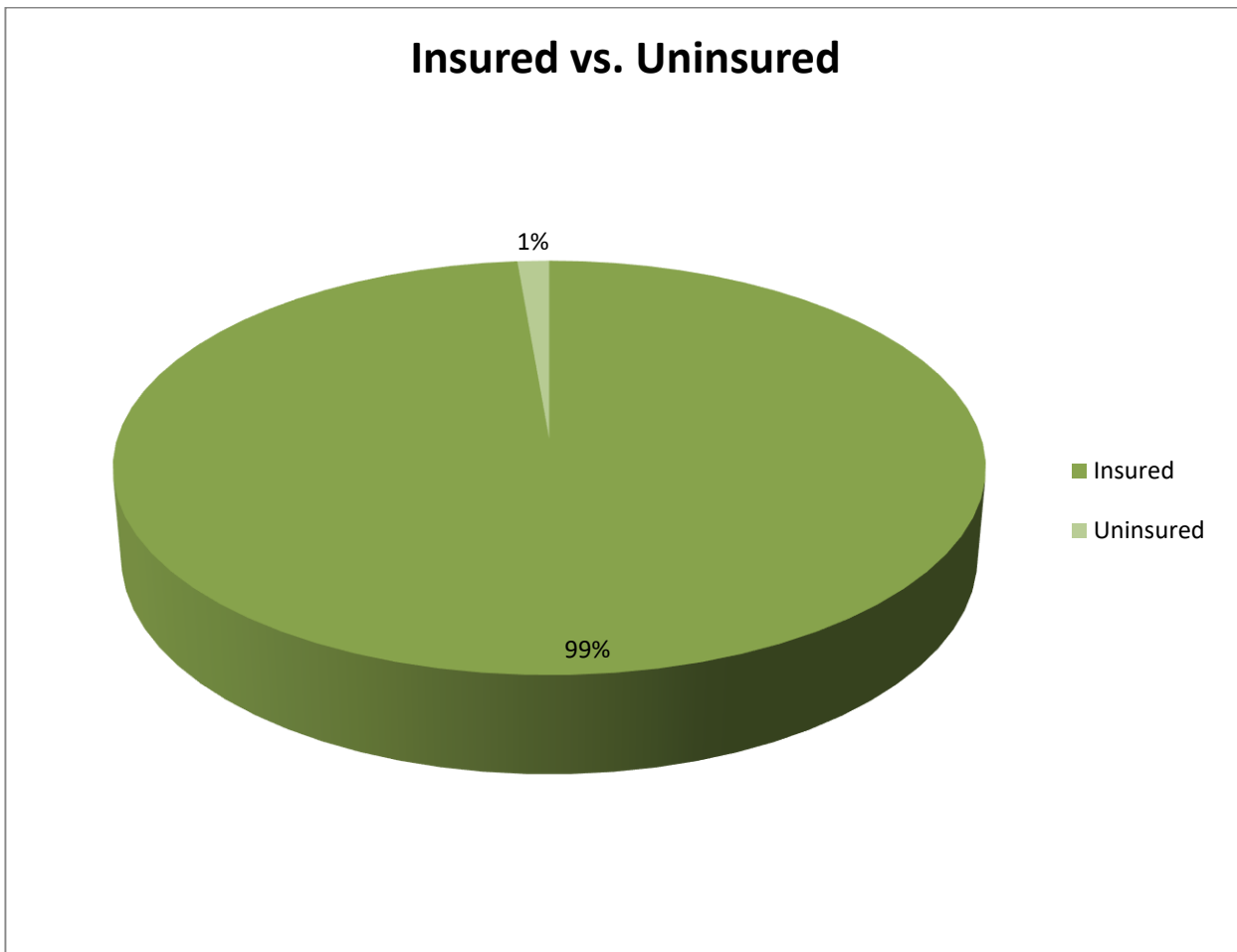
COUNTY	TOTAL REVIEWED	ELIGIBLE	INELIGIBLE	TOTAL EXPENSES	EXPENSES WITH CAPS & DISCOUNTS
ATLANTIC	11	6	5	217,033.64	174,017.19
BERGEN	52	26	22	594,626.75	503,487.07
BURLINGTON	18	11	7	177,700.95	174,686.14
CAMDEN	14	7	7	168,958.72	167,936.03
CAPE MAY	2	1	0	86,696.64	85,460.54
CUMBERLAND	4	1	3	33,875.50	33,875.50
ESSEX	32	17	14	498,659.94	462,901.80
GLOUCESTER	12	6	6	163,986.00	141,460.48
HUDSON	21	14	6	438,215.58	334,422.75
HUNTERDON	7	5	2	144,144.07	144,019.24
MERCER	28	13	14	307,165.00	304,036.38
MIDDLESEX	39	24	9	656,032.25	637,732.37
MONMOUTH	31	19	10	480,494.23	383,681.09
MORRIS	36	15	13	535,422.44	455,839.89
OCEAN	156	110	35	1,023,119.49	1,001,984.22
PASSAIC	39	26	12	573,599.03	526,310.29
SALEM	2	1	1	12,270.23	8,904.51
SOMERSET	8	6	2	106,432.31	106,432.31
SUSSEX	19	9	10	118,729.96	113,554.45
UNION	29	14	13	392,938.36	391,891.34
WARREN	7	6	1	131,378.08	101,532.13
OUT OF STATE	1	0	0	1,426.24	1,426.24
TOTALS	568	337	192	6,862,905.41	6,255,591.96

*Utilization of regulatory caps combined with standardized discounts saved The Fund nearly \$1 million in SFY'17.

SERVICE STATISTICS - SFY '17

Insurance Status of Eligible Parents, SFY'17

Some form of insurance covered the majority of families eligible for assistance, regardless of employment status. The percent of the families insured were 99% and they still had extraordinary out-of-pocket expenses incurred in the care of a child. (See Chart)



Diagnosis - SFY' 17

Review of Categories for Eligible Health Services

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

N.J.A.C. 10:155 identifies the categories of health services that are considered to be eligible and for which a family may submit for review to the Commission. The following summarizes the percentage of total award amount for each category of eligible health services in applications approved by the Commission in SFY'17.

Category of Eligible Health Service	Average	Category of Eligible Health Service	Average
Transportation (purchase, modification of accessible vehicle; travel costs)	24%	Health Insurance	2%
Specialty Pediatric Ambulatory Care	19%	Durable Medical Equipment	6%
Home Modification	2%	Specialty Hospital, Out-of State	2%
Hospital, In-State	5%	Home Health Care	1%
Pharmacy	7%	Disposable Medical Supplies	3%
Ancillary Services	5%	Temporary Shelter	2%
Physician Services	17%	Hospital, Out-of-State	2%
Specialty Hospital, In-State	1%	Funeral Expenses	1%
Long Term Care	1%		

Diagnosis - SFY' 17

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 consistent with provider billing codes.

The International Classification of Diseases World Health Organization's, Clinical Modifications ICD-9-CM codes and descriptions are based on the official U.S. Department of Health and Human Services codes in effect for each 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 following pages provide an unduplicated list of diagnoses and conditions presented to the Commission in SFY'16. 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'17 Eligible Applications

Code	Diagnosis (N=300)
008.61	Intestinal Infection Enteritis Due To Rotavirus
009.1	Colitis Enteritis & Gastroenteritis of Presumed Infectious Origin
075	Infectious Mononucleosis
078.0	Molluscum Contagiosum
078.10	Unspecified Viral Warts
078.82	Epidemic Vomiting Syndrome
079.6	Respiratory Syncytial Virus
088.81	Lyme Disease
112.5	Disseminated Candidiasis
112.85	Candidiasis Of The Intestine
117.9	Other And Unspecified Mycoses
136.1	Behcet's Syndrome
170.9	Malignant Neoplasm of Bone & Articular Cartilage Site Unspecified
171.9	Malignant Neoplasm of Connective and Other Soft Tissue, Site Unspecified

Diagnosis - SFY' 17

Code	Diagnosis (N=300)
186	Malignant Neoplasm Of Testis
189.0	Malignant Neoplasm Of Kidney Except Pelvis
191.1	Malignant Neoplasm Of Frontal Lobe Of Brain
191.6	Malignant Neoplasm Of Cerebellum Not Otherwise Specified
191.9	Malignant Neoplasm Of Brain Unspecified Site
194.0	Malignant Neoplasm Of Adrenal Gland
204.0	Acute Lymphoid Leukemia
204.00	Acute Lymphoid Leukemia, Without Mention of Having Achieved Remission
213.0	Benign Neoplasm Of Bones Of Skull And Face
216.9	Benign Neoplasm Of Skin Site Unspecified
225.0	Benign Neoplasm Of Brain
227.4	Benign Neoplasm Of Pineal Gland
228.09	Hemangioma Of Other Sites
23.19	Other Surgical Extraction Of Tooth
237.5	Neoplasm Uncertain Behavior Brain&Spinal Cord
237.71	Neurofibromatosis, Type 1
237.72	Neurofibromatosis, Type 2
238	Neoplasm Uncertain Bhv Oth&Unspec Sites&Tiss
238.2	Neoplasm Of Uncertain Behavior Of Skin
243	Congenital Hypothyroidism
244.9	Unspecified Hypothyroidism
252.1	Hypoparathyroidism
253.3	Pituitary Dwarfism
253.4	Other Anterior Pituitary Disorders
255	Disorders Of Adrenal Glands
257.2	Other Testicular Hypofunction
259.1	Precocious Sexual Development and Puberty Not Elsewhere Classified
266.2	Other B-Complex Deficiencies
268	Vitamin D Deficiency
268.9	Unspecified Vitamin D Deficiency
269.3	Mineral Deficiency Not Elsewhere Classified
269.9	Unspecified Nutritional Deficiency
270.0	Disturbances Of Amino-Acid Transport
270.4	Disturbances Sulphur-Bear Amino-Acid Metabolism
271.0	Glycogenosis
272.4	Other And Unspecified Hyperlipidemia
272.7	Lipidoses
275.1	Disorders Of Copper Metabolism
275.2	Disorders Of Magnesium Metabolism
275.9	Unspecified Disorder Of Mineral Metabolism
276.51	Dehydration
276.9	Electrolyte And Fluid Disorders Not Elsewhere Classified
277.4	Disorders Of Bilirubin Excretion
277.5	Mucopolysaccharidosis
277.6	Other Deficiencies Of Circulating Enzymes

Diagnosis - SFY' 17

Code	Diagnosis (N=300)
277.86	Peroxisomal Disorders
277.89	Other Specified Disorders Of Metabolism
277.9	Unspecified Disorder Of Metabolism
279.00	Unspecified Hypogammaglobulinemia
279.2	Combined Immunity Deficiency
279.3	Unspecified Immunity Deficiency
279.8	Other Spec Disorders Involving Immune Mechanism
280	Iron Deficiency Anemias
282.5	Sickle-Cell Trait
284.01	Constitutional Red Blood Cell Aplasia
287	Purpura And Other Hemorrhagic Conditions
287.5	Unspecified Thrombocytopenia
288.60	Leukocytosis Unspecified
294.8	Other Persistent Mental Disorders Due to Conditions Classified Elsewhere
296.30	Major Depressive Disorder, Recurrent Episode, Unspecified
296.32	Major Depressive Disorder, Recurrent Episode Moderate
296.33	Major Depressive Affective Disorder, Recurrent Episode, Severe, Without Mention of
296.4	Bipolar I Disorder Most Recent Episode Manic
296.7	Bipolar I Disorder Most Recent Episode Unspecified
296.80	Bipolar Disorder Unspecified
296.90	Unspecified Episodic Mood Disorder
296.99	Other Specified Episodic Mood Disorder
298.0	Depressive Type Psychosis
298.9	Unspecified Psychosis
299	Pervasive Developmental Disorders
299.0	Autistic Disorder Current Or Active State
299.8	Other Specified Pervasive Developmental Disorders, Current or Active State
299.80	Unspecified Pervasive Developmental Disorder
299.81	Other Specified Pervasive Developmental Disorders, Residual State
299.9	Unspecified Pervasive Developmental Disorder
300.00	Anxiety State, Unspecified
300.02	Generalized Anxiety Disorder
300.23	Social Phobia
300.3	Obsessive-Compulsive Personality Disorder
300.4	Dysthymic Disorder
300.9	Unspecified Nonpsychotic Mental Disorder
301.4	Obsessive-Compulsive Personality Disorder
301.83	Borderline Personality Disorder
301.9	Unspecified Personality Disorder
303	Alcohol Dependence Syndrome
303.0	Acute Alcoholic Intoxication
304.0	Opioid Type Dependence
304.30	Nondependent Alcohol Abuse Unspecified Drunkenness
304.40	Amphetamine and other psychostimulant dependence, unspecified
304.8	Comb Drug Dependence Excluding Opioid Drug
305.00	Alcohol Abuse, Unspecified

Diagnosis - SFY' 17

Code	Diagnosis (N=300)
307.50	Eating Disorder, Unspecified
307.51	Bulimia Nervosa
307.59	Other Disorders of Eating
307.9	Other and Unspecified Special Symptoms or Syndromes, Not Elsewhere Classified
309.28	Adjustment Disorder with Mixed Anxiety and Depressed Mood
309.81	Posttraumatic Stress Disorder
311	Depressive Disorder, Not Elsewhere Classified
312.34	Intermittent Explosive Disorder
313.81	Oppositional defiant disorder
313.89	Other Emotional Disturbances of Childhood or Adolescence
314.0	Attention Deficit Disorder of Childhood
314.00	Attention Deficit Disorder without Mention of Hyperactivity
314.01	Attention Deficit Disorder with Hyperactivity
315.32	Mixed Receptive-Expressive Language Disorder
315.34	Speech and Language Developmental Delay Due to Hearing Loss
315.4	Developmental Coordination Disorder
315.5	Mixed Development Disorder
315.8	Other Specified Delay In Development
318	Other Specified Intellectual Disabilities
318.1	Severe Intellectual Disabilities
318.2	Insomnia D/T Medical Cond Classified Elsewhere
319	Unspecified Intellectual Disabilities
323.61	Infectious Acute Disseminated Encephalomyelitis (ADEM)
323.81	Other Causes of Encephalities and Encephalomyelitis
327.01	Insomnia Due to Medical Condition Classified Elsewhere
327.23	Obstructive Sleep Apnea(Adult)(Pediatric)
327.27	Central Sleep Apnea in Conditons Classified Elsewhere
330	Cerebral Degenerations Usually Manifest in Childhood
330.0	Leukodystrophy
330.8	Other Specified Cerebral Degenerations in Childhood
331.	Other Cerebral Degeneration
331.4	Obstructive Hydrocephalus
331.89	Genetic Torsion Dystonia
333	Other Degenerative Diseases of the Basal Ganglia
333.2	Myoclonus
333.6	Generic Torsion Dystonia
333.71	Athetoid Cerebral Palsy
333.79	Other Acquired Torsion Dystonia
335.1	Unspecified Hemiplegia
335.19	Infantile Cerebral Palsy
336.0	Syringomyelia and Syringobulbia
342.9	Hemiplegia

Diagnosis - SFY' 17

Code	Diagnosis (N=300)
343	Infantile Cerebral Palsy
343.0	Quadriplegic Infantile Cerebral Palsy
343.10	Congenital Diplegia
343.2	Congenital Quadriplegia
343.8	Other Specified Infantile Palsy
343.9	Infantile Cerebral Palsy, Unspecified
344.0	Quadriplegia And Quadriparesis
344.00	Quadriplegia, Unspecified
344.09	Other Quadriplegia
344.1	Paraplegia
345.0	Generalized Non-Convulsive Epilepsy
345.01	Generalized Convulsive Epilepsy With Intractable Epilepsy
345.1	Generalized Convulsive Epilepsy
345.10	Generalized Convulsive Epilepsy Without Mention of Intractable Epilepsy
345.4	Unspecified Epilepsy
345.5	Localization-Related (Focal)(Partial) Epilepsy and Epileptic Syndromes With Complex
345.50	Localization-Related (Focal)(Partial) Epilepsy and Epileptic Syndromes With Complex
345.8	Other Forms of Epilepsy and Recurrent Seizures
345.9	Epilepsy Unspecified
345.90	Epilepsy, Unspecified, Without Mention of Intractable Epilepsy
347.0	Narcolepsy
348.0	Encephalopathy Unspecified
348.1	Anoxic Brain Damage
348.2	Benign Intracranial Hypertension
348.3	Encephalopathy, Not Elsewhere Classified
348.4	Compression of Brain
348.89	Other Conditions of Brain
348.9	Other and Unspecified Disorders of the Nervous System
349.9	Unspecified Disorders of Nervous System
350.2	Atypical Face Pain
356.9	Unspecified Hereditary & Idiopathic Peripheral Neuropathy
358	Myoneural Disorders
358.00	Myasthenia Gravis Without Exacerbation
358.1	Myasthenic Syndromes Diseases Classified Elsewhere
359	Muscular Dystrophies And Other Myopathies
359.1	Hereditary Progressive Muscular Dystrophy
359.8	Other Myopathies
362.16	Retinal Neovascularization Not Otherwise Specified
362.20	Retinopathy Of Prematurity Unspecified
362.3	Retinal Vascular Occlusion
365	Glaucoma
366	Cataract
366.0	Infantile Juvenile And Presenile Cataract
366.00	Unspecified Nonsenile Cataract

Code	Diagnosis (N=300)
366.9	Unspecified Cataract
367.1	Myopia
367.21	Regular Astigmatism
368.00	Unspecified Amblyopia
368.03	Refractive Amblyopia
368.31	Suppression Of Binocular Vision
369	Blindness And Low Vision
369.00	Blindness Both Eyes Impair Level Not Further Specified
369.9	Unspecified Visual Loss
370.9	Unspecified Keratitis
371.0	Corneal Scars And Opacities
371.60	Unspecified Keratoconus
375.56	Stenosis Of Nasolacrimal Duct Acquired
377.0	Papilledema
377.10	Unspecified Optic Atrophy
377.49	Other Disorder Of Optic Nerve
377.75	D/O Visual Cortex Associated With Cortical Blindness
378.0	Esotropia
378.00	Unspecified Esotropia
378.52	Paralytic Strab Third/Oculomotor Nervous Palsy Total
378.71	Duanes Syndrome
378.83	Convergence Insufficiency/Palsy Binocular Eye Movement
379.3	Aphakia And Other Disorders Of Lens
379.5	Nystagmus And Other Irregular Eye Movements
379.50	Unspecified Nystagmus
379.51	Congenital Nystagmus
379.57	Nystagmus With Deficiencies Saccadic Eye Movements
379.58	Nystagmus With Deficiencies Smooth Pursuit Movements
379.91	Pain In Or Around Eye
381.10	Simple/Unspecified Chronic Serous Otitis Media
381.81	Dysfunction Of Eustachian Tube
382.00	Acute Suppurative Otitis Media Without Spontaneous Rupture of Eardrum
384.2	Perforation Of Tympanic Membrane
385.11	Adhesions Of Drum Head To Incus
385.32	Cholesteatoma Of Middle Ear
385.33	Cholesteatoma Of Middle Ear And Mastoid
388.40	Unspecified Abnormal Auditory Perception
388.43	Impairment Of Auditory Discrimination
388.45	Acquired Auditory Processing Disorder
389	Hearing Loss
389.03	Conductive Hearing Loss, Middle Ear
401	Essential Hypertension
401.1	Essential Hypertension, Benign
401.9	Unspecified Essential Hypertension
414.8	Other Specified Forms Chronic Ischemic Heart Disease
415.1	Pulmonary Embolism And Infarction
416.0	Primary Pulmonary Hypertension

Legislative and Regulatory Changes

There were no amendments to the Commission's enabling legislation during the fiscal year. There were also no changes made to the Commission's regulations during the fiscal year.

Fiscal Issues

The Commission continued prudent fiscal practices in SFY'17 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 million in SFY'17. Since the discount policy was adopted in 1994, the Commission realized savings of nearly \$33 million.

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'17, 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 www.njcatastrophicfund.org is also available for the public to obtain information and submit an application.

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 18, 2017, during which 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. The FAC supports the Commission in disseminating program information on the local level. In SFY'17, the FAC had 132 families.

Outreach efforts continued throughout the fiscal year. The Fund attended and/or exhibited at several conferences and fairs, including the American Academy of Pediatrics, NJ Conference of Mayors, NJ Association of Counties, Women in Municipal Government, Governor's Conference for Women, Dental Expo 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:

*“Thank You so much for the help and securing our refund to be able to further help our child”
(Lakewood, Ocean County, New Jersey)*

“Thank You for making my family’s holidays the happiest ever”.
(Woodland Park, Passaic County, New Jersey)

*“We could not Thank You enough for your understanding and putting an effort to help us go through these difficulties with finances”
(Union City, Hudson County, New Jersey)*

*“On behalf of myself and my family we would like to genuinely thank the CICRF for their help and support over the past several years”
(Paramus, Bergen County, New Jersey)*

“ ”

“ ”

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'17 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 help available through this valuable state resource. With an active public information plan in place, the Commission is committed to promoting the Fund to its expanding population.

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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 percent 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 percent of the first \$100,000 of annual income of a family plus 15 percent 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.

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§ 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.

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§ 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

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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.

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§ 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.

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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.

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“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.

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“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.

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§ 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.

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§ 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:

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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.

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§ 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 percent of income):	3,000
Amount of Eligible Medical Expenses not Covered by Insurance:	15,000
Family Responsibility (Exceeding 10 percent 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 percent of income):	8,000
Amount of Eligible Medical Expenses not Covered by Insurance:	15,000
Family Responsibility (Exceeding 10 percent 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 percent of the first \$ 100,000 or 10,000	
Exceeding 15 percent of the excess over \$100,000 or 3,000	
Amount of Eligible Medical Expenses not Covered by Insurance:	15,000
Family Responsibility (Exceeding 10 percent 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, MD, CICRF Chairperson

Claudia L. Marchese, Esq., CICRF
Executive Director