

**July 2009 - June 2010**

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

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



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

**Chris Christie, Governor**

Kim Guadagno, Lieutenant Governor  
Jennifer Velez, Commissioner of Human Services  
Jane Schreadley Lorber, CICRF Chairperson  
Claudia L. Marchese, Esq., CICRF Executive Director

# CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION

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

Dear Governor Christie:

As Chairperson of the Catastrophic Illness in Children Relief Fund Commission, 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 2009 to June 2010.**

In State Fiscal Year 2010, the Catastrophic Illness in Children Relief Fund Commission approved approximately \$7.1 million in grant awards for **318** families. Some of these families were without health care coverage at the time they incurred significant medical expenses for their children. A remarkable 93 percent of awards, however, were approved for families who were insured and were still burdened with catastrophic medical expenses related to the care of their children. The diverse needs of New Jersey families continue to demonstrate the value of this unique financial safety net.

Since the first grant awards were approved in December 1989, approximately **\$131M** has been awarded to over 5,400 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,

*Jane S. Lorber*

Jane S. Lorber,  
Chairperson

## EXECUTIVE SUMMARY

The Catastrophic Illness in Children Relief Fund Commission (The Fund) approved \$7.1M in grant awards for families in need during State Fiscal Year 2010 (SFY'10). 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, 2010, approximately \$131M has been awarded to New Jersey families.

The data on awards approved in SFY'10 demonstrates that financial help was available to meet the diverse needs of 318 New Jersey families with awards ranging from \$1,168 to \$106,043. The average award per family was \$21,413. 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 \$4.2M in SFY10. Since the inception of The Fund, the Commission achieved close to \$20M 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 as many New Jersey families possible

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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*N.J.S.A. 26:2-148 et seq., The Catastrophic Illness in Children Relief Fund Act  
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 acknowledges the contributions of member designees in SFY'10, including:

William A.B. Ditto of the NJ Department of Human Services  
Pauline Lisciotta of the NJ Department of Health and Senior Services  
Hans Goff / 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.

## 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 exceeds the established eligibility threshold. In State Fiscal Year 2010 (SFY'10), 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. In SFY'10, the Commission provided assistance to forty-nine young adults between the ages of 18 and 21.

The family must be a resident of New Jersey for at least three months prior to submission of an application. Temporary residents, including 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 in 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 to access to health insurance for many families in New Jersey. For those 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 is often unable to afford the cost of health premiums

Yet, 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 and increasingly appear in applications to The Fund.

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 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 still 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 is allocated 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' 10, 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 Senior Services, 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 compliance with Commission policies and decisions.

Staff in the State Office of the Commission provides guidance needed by the family to initially submit provider bills to insurance, seek Charity Care determinations, or otherwise utilize available resources before submitting an application for financial assistance. Staff 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 DHSS. The Commission has continued its grant to SCAEIS for contracted services from the Special Child Health Services (SCHS) Case Management Units in each county to ensure that families have access to program information and referral at the local level.

### 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' 10, the Commission's Public Information Plan was designed to enhance public awareness of "The Fund" through paid advertising, community outreach and public relations efforts.

The distinct and creative designs, which identify the Program, were re-designed with input from Winning Edge Communications (WEC), staff and the Executive Director. WEC is contracted as the advertising/public relations firm for The Fund, effective October 22, 2007 and terminating October 31, 2010. The unique 800-phone number continued to be available for the public as the Family Information Line, 1-800-335-FUND. The Fund's website is also available for the public, [www.njcatastrophicfund.org](http://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 with disabled children continued and when possible presentations to these groups were made.

The Commission's Annual Meeting was held on June 23, 2010, where the Commission joined members of the Family Advisory Committee (FAC) and guests. meeting was held in the War Memorial Building and honored guests included DHS Commissioner Jennifer Velez, Commission Members, staff, and many families and applicant children. FAC supports the Commission in disseminating program information on the local level. Television stations ran spots of this important event. SFY' 10, the FAC had 129 families.

### 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 over to the State Treasurer for deposit into The Fund. Interest earned on money collected is credited to The Fund.

## CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND

### Fund Balance

	ACTUAL FY'09	ACTUAL FY'10
<b>REVENUES:</b>		
FUND BALANCE JULY 1	\$ 6,047,787	\$ 958,943
SERVICES AND ASSESSMENTS	\$ 8,959,711	\$ 7,980,027
INVESTMENT EARNINGS	\$ 61,473	\$ 7,467
CONTRIBUTION (DONATIONS)	\$ 0	\$ 135
<b>TOTAL REVENUE</b>	<b>\$ 15,068,971</b>	<b>\$ 8,946,572</b>
<b>EXPENDITURES:</b>		
PHYSICAL AND MENTAL HEALTH	\$ (105,812)	\$ (107,927)
FAMILIES AND PROVIDERS	\$ (7,803,530)	\$ (6,856,933)
OPERATING EXPENSES	\$ (1,200,686)	\$ (1,483,348)
<b>TOTAL EXPENDITURES</b>	<b>\$ (9,110,028)</b>	<b>\$ (8,448,208)</b>
<b>OTHER FINANCIAL USES:</b>		
Due to the budget crisis, there was a diversion of funds from our account in the amount of \$5M in FY'09.		
<b>TOTAL OTHER FINANCIAL USES</b>	<b>\$ (5,000,000)</b>	<b>N/A</b>
<b>TOTAL EXPENDITURES &amp; OTHER FINANCIAL</b>	<b>\$ (14,110,028)</b>	<b>\$ (8,448,208)</b>
<b>FUND BALANCE JUNE 30</b>	<b>\$ 958,943</b>	<b>\$ 498,364</b>

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.

## II. SERVICE STATISTICS - SFY '10

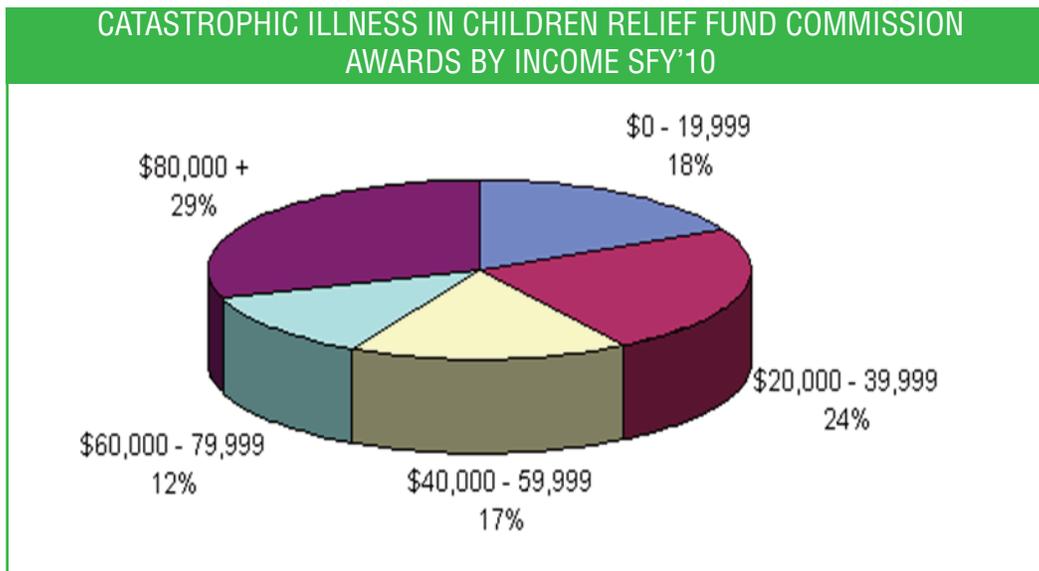
### Catastrophic Illness in Children Relief Fund Commission

In SFY' 10, the Commission processed 342 applications. Of those applications, the Commission approved \$7.1M for 318 families.

TOTAL AWARDS APPROVED	\$7.1M
TOTAL APPLICATIONS APPROVED	318
Range of Awards	\$1,168 - \$106,043
Average	\$21,413
Range of Income	\$0—\$529,418
Average	\$64,224
Average Expense: Income	72.3%

The applications reviewed by the Commission reflected a range of uncovered expenses among families in need. Awards approved by the Commission in SFY' 10 ranged from \$1,168 to \$106,043, with an average award of \$21,413. Similarly, the range of expense-to-income threshold was as dramatic as the range in awards, spanning from 10 percent to 2,103 percent.

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 disproportionately high for them.



## II. SERVICE STATISTICS - SFY '10

### Catastrophic Illness in Children Relief Fund Commission

**Table 1**

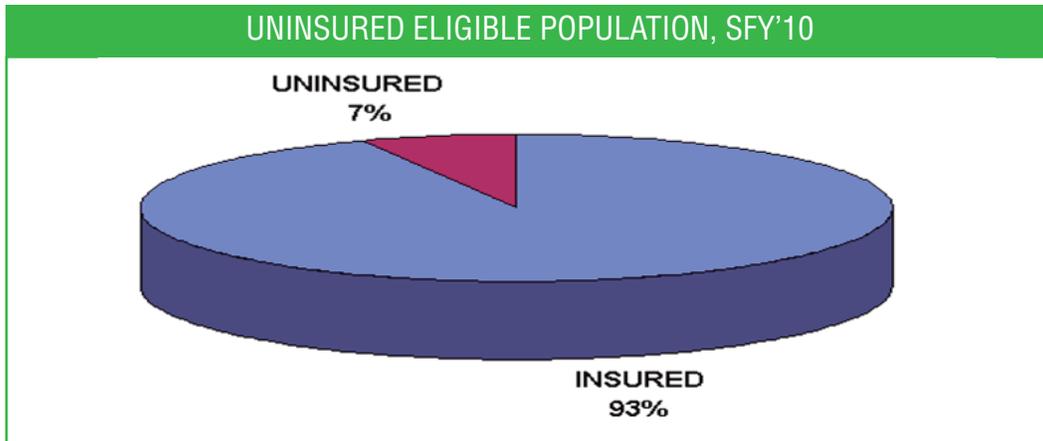
#### CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION APPLICATIONS BY COUNTY SFY '10

COUNTY	TOTAL REVIEWED	ELIGIBLE	INELIGIBLE	EXPENSES	FUND DISTRIBUTION
ATLANTIC	8	8	0	740,742	248,001
BERGEN	28	26	2	823,084	794,974
BURLINGTON	17	17	0	1,282,793	450,291
CAMDEN	19	15	4	343,487	282,222
CAPE MAY	3	3	0	164,929	152,145
CUMBERLAND	2	2	0	66,834	65,649
ESSEX	21	18	3	767,357	650,589
GLOUCESTER	12	9	3	2,171,158	380,761
HUDSON	13	12	1	206,148	205,556
HUNTERDON	6	6	0	193,414	183,356
MERCER	18	17	1	365,393	297,894
MIDDLESEX	18	16	2	430,187	379,592
MONMOUTH	25	23	2	434,709	381,200
MORRIS	24	24	0	839,858	591,568
OCEAN	68	66	2	622,359	608,494
PASSAIC	25	22	3	602,381	482,430
SALEM	3	3	0	81,720	54,833
SOMERSET	7	6	1	182,389	159,629
SUSSEX	7	7	0	175,949	163,139
UNION	16	16	0	762,956	539,256
WARREN	2	2	0	38,276	38,276
<b>TOTALS</b>	<b>342</b>	<b>318</b>	<b>24</b>	<b>11,296,123</b>	<b>7,109,855</b>

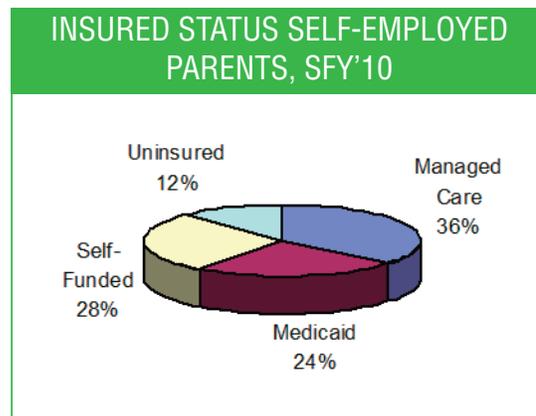
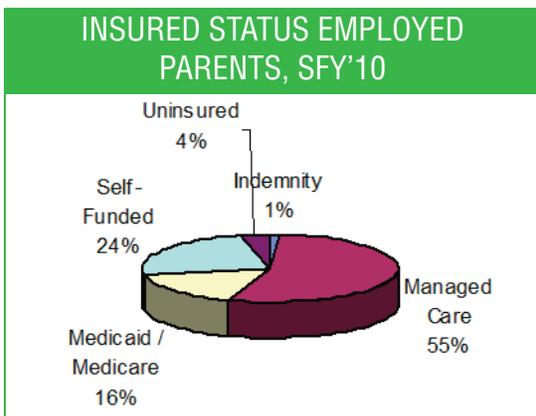
\*Utilization of regulatory caps combined with standardized discounts saved The Fund approximately \$4.2M in SFY'10.

**Insurance Status of Eligible Parents, SFY'10**

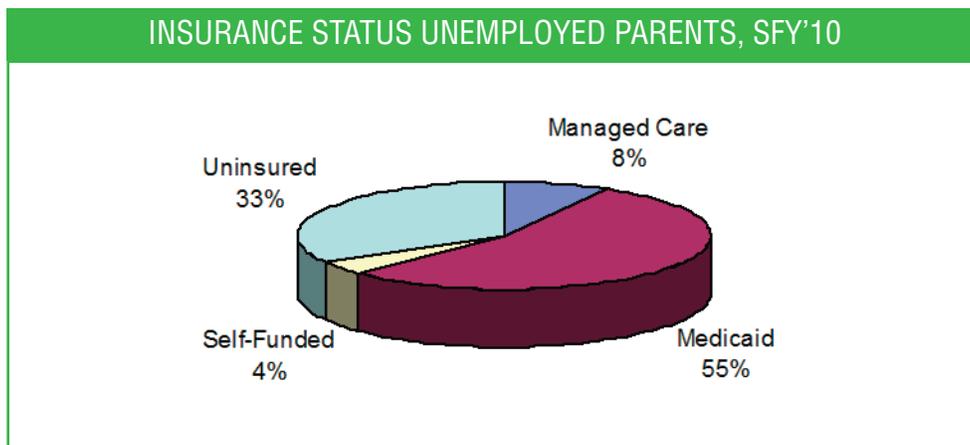
The majority of families eligible for assistance were covered by some form of insurance, regardless of employment status. More than 93 percent of the families were insured and still had extraordinary out-of-pocket expenses incurred in the care of a child. (See Chart)



An analysis of applications by employment status reflects that the majority of the employed and self-employed parents were insured by private insurance, Medicaid, or both. Of the employed parents, one percent were covered by indemnity plans, 55 percent were covered by managed care, 24 percent were covered by self funded, and 16 percent had children who were covered by Medicaid/care. Self-funded plans represent a combination of health plans that are outside the regulatory jurisdiction of DOBI and DHSS. They may include, but are not limited to, trade unions and most self-funded employer groups that have an ERISA exemption, which excludes them from offering the state mandated benefits as part of their insurance plans. Of the self-employed parents, 36 percent were covered by managed care, 24 percent had children who were covered by Medicaid, and 28 percent of these families were covered by self-funded plans. The uninsured for each group reflects four and twelve percent, respectively. (See Charts)



The number of unemployed parents eligible for assistance from The Fund confirm that insurance is connected to employment. Of this group, 8 percent were covered by managed care, 55 percent had Medicaid coverage, and 4 percent had self-funded plans for the child. The uninsured in this group of parents was 33 percent. Some parents, though unemployed, were able to continue insurance through the Consolidated Omnibus Budget Reconciliation Act (COBRA) when it was available and affordable. Others had insurance coverage available only for a short period of time after employment ended. Many were uninsured, as they were unable to purchase insurance directly due to the high cost of self-pay coverage. (See chart below):



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

**Public Need for the Fund**

In SFY' 10, 318 eligible families obtained assistance for uncovered expenses due to a variety of circumstances. Assistance offset expenses for the following general categories\*:

- <1% Pre-existing condition
- <1% Lack of preauthorization
- 30% Expenses exceeded charges allowed by insurance
- 72% Non-covered services
- 28% Non-participating providers
- 50% Co-payments and deductibles

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

In SFY' 10, 21 families eligible for financial assistance were uninsured. This represents seven percent of all the eligible families. The Commission anticipates a continued demand for The Fund by parents whose expenses were incurred during a break in health insurance coverage. In SFY' 10, the Commission reviewed four applications for expenses dating back to 2004. It may review expenses dating back to 1988.

### 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'10.

Category of Eligible Health Service	Average	Category of Eligible Health Service	Average
Hospital, In-State	27%	Pharmacy	1%
Transportation	18%	Disposable Medical Supplies	<1%
Hospital, Out-Of-State	11%	Funeral Expenses	<1%
Specialty Hospital, Out-Of-State	10%	Ancillary Services	<1%
Physician Services	9%	Home Health Care	<1%
Specialty Pediatric Ambulatory Care	8%	Temporary Shelter	<1%
Home Modification	7%	Long Term Care	<1%
Health Insurance	3%	Telephone	<1%
Durable Medical Equipment	2%	Experimental Services	0%
Specialty Hospital, In-State	2%		

### Review of Medical Conditions

Families apply to the Catastrophic Illness in Children Relief Fund for their children's 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'10. 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

Diagnosis (N=227)	Code
24 Completed Weeks Of Gestation	765.22
25-26 Completed Weeks Of Gestation	765.23
29-30 Completed Weeks Of Gestation	765.25
33-34 Completed Weeks Of Gestation	765.27
Acute Appendicitis	540
Acute Appendicitis Without Mention Of Peritonitis	540.9
Acute Kidney Failure, Unspecified	584.9
Acute Upper Respiratory Infections Of Unspecified Site	465.9
Adjustment Disorder With Mixed Anxiety And Depressed Mood	309.28
Adjustment Reaction	309
Altered Mental Status	780.97
Anemia Of Neonatal Prematurity	776.6
Anorexia Nervosa	307.1
Anxiety	300.
Anxiety, Dissociative And Somatoform Disorders	300
Aphakia And Other Disorders Of Lens	379.3
Attention Deficit Disorder Of Childhood With Hyperactivity	314.01
Autistic Disorder	299.0
Bilateral Cleft Lip, Complete	749.13
Bipolar Disorder, Unspecified	296.80
Bipolar I Disorder, Most Recent Episode (Or Current) Depressed, Severe, Without Mention Of Psychotic Behavior	296.53
Blindness Of Both Eyes, Impairment Level Not Further Specified	369.00
Borderline Personality Disorder	301.83
Bulimia Nervosa	307.51
Buphthalmos	743.2
Certain Congenital Musculoskeletal Deformities	754.
Cervicalgia	723.1
Chest Pain, Unspecified	786.50
Cholecystitis, Unspecified	575.10
Chronic Airway Obstruction, Not Elsewhere Classified	496
Chronic Bronchitis	491
Chronic Respiratory Disease Arising In The Perinatal Period	770.7
Cleft Palate With Cleft Lip	749.2
Coarctation Of Aorta (Preductal) (Postductal)	747.10
Common Truncus	745.0
Communicating Hydrocephalus	331.3
Congenital Anomalies Of Diaphragm	756.6
Congenital Anomalies Of Eye	743
Congenital Anomalies Of Pulmonary Artery	747.3
Congenital Anomalies Of Skull And Face Bones	756.0
Congenital Capsular And Subcapsular Cataract	743.31
Congenital Cytomegalovirus Infection	771.1

## II. SERVICE STATISTICS - SFY '10

### Catastrophic Illness in Children Relief Fund Commission

Diagnosis (N=227)	Code
Congenital Dislocation Of Hip	754.3
Congenital Hydrocephalus	742.3
Congenital Hypertrophic Pyloric Stenosis	750.5
Congenital Musculoskeletal Deformities Of Skull, Face, And Jaw	754.0
Congenital Polycystic Kidney, Unspecified Type	753.12
Congenital Reduction Deformities Of Brain	742.2
Congenital Stenosis Of Pulmonary Valve	746.02
Congenital Tracheoesophageal Fistula, Esophageal Atresia And Stenosis	750.3
Congenital Tricuspid Atresia And Stenosis	746.1
Convergence Excess Or Spasm In Binocular Eye Movement	378.84
Convergence Insufficiency Or Palsy In Binocular Eye Movement	378.83
Convulsions	780.3
Cortex (Cerebral) Contusion Without Mention Of Open Intracranial Wound, State Of Consciousness Unspecified	851.00
Delayed Milestones	783.42
Dental Caries	521.0
Dentofacial Anomalies, Including Malocclusion	524
Dentofacial Functional Abnormality, Unspecified	524.50
Depressive Disorder, Not Elsewhere Classified	311
Developmental Coordination Disorder	315.4
Diabetes Mellitus	250.
Diabetes Mellitus Without Mention Of Complication, Type I [Juvenile Type], Not Stated As Uncontrolled	250.01
Diabetes With Ketoacidosis, Type I [Juvenile Type], Uncontrolled	250.13
Disorder Of Bone And Cartilage, Unspecified	733.90
Disorders Of Mitochondrial Metabolism	277.87
Disorders Of Visual Cortex Associated With Cortical Blindness	377.75
Down's Syndrome	758.0
Drug Dependence	304
Dysphagia	787.2
Edwards' Syndrome	758.2
Embolism And Thrombosis Of Unspecified Site	453.9
Encephalitis, Myelitis, And Encephalomyelitis In Viral Diseases Classified Elsewhere	323.0
Encephalocele	742.0
Encephalopathy, Not Elsewhere Classified	348.3
Endometriosis	617
Epilepsy And Recurrent Seizures	345
Episodic Mood Disorders	296
Epistaxis	784.7
Esophageal Reflux	530.81
Extreme Fetal Immaturity, 500-749 Grams	765.02
Febrile Convulsions (Simple), Unspecified	780.31
Feeding Difficulties And Mismanagement	783.3
Femoral Hernia Without Mention Of Obstruction Or Gangrene, Bilateral	553.02
Fetus Or Newborn Affected By Multiple Pregnancy Of Mother	761.5
Flaccid Hemiplegia	342.0
Fracture Of Clavicle	810

## II. SERVICE STATISTICS - SFY '10

### Catastrophic Illness in Children Relief Fund Commission

Diagnosis (N=227)	Code
Functional Digestive Disorders, Not Elsewhere Classified	564
Generalized Convulsive Epilepsy	345.1
Hearing Loss	389
Hereditary Progressive Muscular Dystrophy	359.1
Hirschsprung's Disease And Other Congenital Functional Disorders Of Colon	751.3
Huntington's Chorea	333.4
Hypersomnia With Sleep Apnea, Unspecified	780.53
Hypertensive Chronic Kidney Disease, Unspecified	403.9
Hypertensive Chronic Kidney Disease, Unspecified, With Chronic Kidney Disease Stage V Or End Stage Renal Disease	403.91
Hypertensive Encephalopathy	437.2
Hypocalcemia	275.41
Hypospadias	752.61
Idiopathic Myocarditis	422.91
Impairment Of Auditory Discrimination	388.43
Infantile Spasms	345.6
Influenza	487
Inguinal Hernia	550
Inguinal Hernia, Without Mention Of Obstruction Or Gangrene	550.9
Injury, Other And Unspecified, Trunk	959.1
Intracranial Injury Of Other And Unspecified Nature	854
Intraventricular Hemorrhage	772.1
Keratoconus	371.6
Kyphoscoliosis And Scoliosis	737.3
Lack Of Coordination	781.3
Lack Of Expected Normal Physiological Development	783.4
Less Than 24 Completed Weeks Of Gestation	765.21
Lump Or Mass In Breast	611.72
Lyme Disease	088.81
Major Depressive Disorder, Recurrent Episode, Unspecified	296.30
Major Depressive Disorder, Single Episode, Unspecified	296.20
Malignant Neoplasm Of Connective And Other Soft Tissue Of Lower Limb, Including Hip	171.3
Malignant Neoplasm Of Long Bones Of Lower Limb	170.7
Malignant Neoplasm Of Temporal Lobe Of Brain	191.2
Metabolic Encephalopathy	348.31
Methicillin Resistant Staphylococcus Aureus	041.12
Microcephalus	742.1
Microphthalmos	743.1
Mixed Hearing Loss, Bilateral	389.22
Mixed Receptive-Expressive Language Disorder	315.32
Muscular Dystrophies And Other Myopathies	359
Myopia	367.1
Necrotizing Enterocolitis In Newborn	777.5
Neoplasm Of Uncertain Behavior Of Brain And Spinal Cord	237.5
Neoplasm Of Unspecified Nature Of Brain	239.6

## II. SERVICE STATISTICS - SFY '10

### Catastrophic Illness in Children Relief Fund Commission

Diagnosis (N=227)	Code
Nephrotic Syndrome	581
Neurogenic Bladder, NOS	596.54
Obsessive-Compulsive Disorders	300.3
Obstructive Hydrocephalus	331.4
Opioid Type Dependence	304.0
Oppositional Defiant Disorder	313.81
Organic Sleep Disorders	327
Osteogenesis Imperfecta	756.51
Other Adverse Food Reactions, Not Elsewhere Classified	995.7
Other And Unspecified Congenital Anomalies	759
Other And Unspecified Disorders Of Eating	307.5
Other And Unspecified Disorders Of Metabolism	277
Other And Unspecified Noninfectious Gastroenteritis And Colitis	558.9
Other And Unspecified Ovarian Cyst	620.2
Other And Unspecified Postsurgical Nonabsorption	579.3
Other B-Complex Deficiencies	266.2
Other Cerebral Degeneration	331.89
Other Congenital Anomaly Of Larynx, Trachea, And Bronchus	748.3
Other Congenital Hamartoses, Not Elsewhere Classified	759.6
Other Diseases Of Nasal Cavity And Sinuses	478.19
Other Dyspnea And Respiratory Abnormalities	786.09
Other Preterm Infants	765.1
Other Preterm Infants, 1,250-1,499 Grams	765.15
Other Proliferative Retinopathy	362.2
Other Respiratory Problems Of Newborn After Birth	770.89
Other Specified Cerebral Degenerations In Childhood	330.8
Other Specified Congenital Anomalies Of Kidney	753.3
Other Specified Congenital Anomalies Of Nervous System	742.8
Other Specified Disorders Of The Teeth And Supporting Structures	525.8
Other Specified Mental Retardation	318
Other Specified Multiple Congenital Anomalies, So Described	759.89
Other Speech Disturbance	784.5
Other Spino Cerebellar Diseases	334.8
Other Spontaneous Pneumothorax	512.8
Other, Mixed, Or Unspecified Nondependent Drug Abuse	305.9
Panic Disorder Without Agoraphobia	300.01
Personality Change Due To Conditions Classified Elsewhere	310.1
Pervasive Developmental Disorders	299
Pigmentary Retinal Dystrophy	362.74
Pneumonitis Due To Inhalation Of Food Or Vomitus	507.0
Poisoning By Other And Unspecified Drugs And Medicinal Substances	977
Post Traumatic Stress Disorder	309.81
Posterior Scleritis	379.07
Prader-Willi Syndrome	759.81

## II. SERVICE STATISTICS - SFY '10

### Catastrophic Illness in Children Relief Fund Commission

Diagnosis (N=227)	Code
Profound Mental Retardation	318.2
Respiratory Conditions Due To Unspecified External Agent	508.9
Respiratory Distress	769.
Respiratory Distress Syndrome In Newborn	769
Retinal Vascular Occlusion	362.3
Retinopathy Of Prematurity, Stage 1	362.23
Retinopathy Of Prematurity, Stage 3	362.25
Retinopathy Of Prematurity, Stage 4	362.26
Retinopathy Of Prematurity, Unspecified	362.20
Rhabdomyolysis	728.88
Rotation Of Tooth/Teeth	524.35
Scoliosis	737.
Scoliosis Associated With Other Condition	737.43
Secondary Malignant Neoplasm Of Other Specified Sites	198.89
Selective Mutism	313.23
Sensorineural Hearing Loss	389.1
Sickle-Cell Disease	282.6
Spasm Of Muscle	728.85
Specified Congenital Anomaly Of Anterior Chamber, Chamber Angle, And Related Structures	743.44
Spina Bifida With Hydrocephalus	741.0
Spinal Muscular Atrophy	335.1
Stenosis Of Larynx	478.74
Suppurative And Unspecified Otitis Media	382
Syncope And Collapse	780.2
Tourette's Disorder	307.23
Transposition Of Great Vessels, Double Outlet Right Ventricle	745.11
Tuberous Sclerosis	759.5
Undescended Testis	752.51
Unspecified Acute Myocarditis	422.90
Unspecified Anterior Horn Cell Disease	335.9
Unspecified Asthma	493.9
Unspecified Cataract	366.9
Unspecified Cerebral Artery Occlusion With Cerebral Infarction	434.91
Unspecified Condition Of Brain	348.9
Unspecified Congenital Anomaly Of Brain, Spinal Cord, And Nervous System	742.9
Unspecified Congenital Anomaly Of Heart	746.9
Unspecified Delay In Development	315.9
Unspecified Disorder Of Eye Movements	378.9
Unspecified Disorder Of Liver	573.9
Unspecified Disorder Of Muscle, Ligament, And Fascia	728.9
Unspecified Emotional Disturbance Of Childhood Or Adolescence	313.9
Unspecified Episodic Mood Disorder	296.90
Unspecified Infantile Cerebral Palsy	343.9
Unspecified Intestinal Malabsorption	579.9

<b>Diagnosis (N=227)</b>	<b>Code</b>
Unspecified Intestinal Obstruction	560.9
Unspecified Myopathy	359.9
Unspecified Osteoporosis	733.00
Urinary Tract Infection, Site Not Specified	599.0
Vesicoureteral Reflux	593.7
Vitreous Anomaly, Congenital	743.51
Werdnig-Hoffmann Disease	335.0

### Fiscal Issues

The Commission continued prudent fiscal practices in SFY'10 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 \$4M in SFY'10. Since the discount policy was adopted in 1994, the Commission realized savings of approximately \$23M.

### Public Information Efforts

The Fund has seen a significant increase in the number of requested and received applications. In SFY'10, NJN continued to run the general service announcement (GSA), featuring Kelly Rouba, a former recipient of The Fund. Airtime included spots on several NJN children programs, primetime shows, and on programs of the NJ Lottery. Program information requests were generated from a variety of sources, including but not limited to healthcare providers, schools, special children's programs, and other State programs. Special Child Health Services also was instrumental in referring many families to the program. In addition, The Fund continues to receive requests for information through the new website, [www.njcatastrophicfund.org](http://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 Conference of Mayors, the NJ Association of Counties and the National Association of Social Workers. Additional outreach efforts included program information mailings to Family Advisory Committee members, county Special Child Health Case Management units, parents of ill children identified through our newspaper clipping service and to reporters who have written stories on ill children.

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.

In July 2009, letters were sent to recent recipient families, inviting them to participate as volunteer members of the Commission's Family Advisory Committee (FAC) and to assist the Commission in disseminating program information at a local level. Letters also were sent to existing FAC members, asking if they wished to continue participation, based on their interest and availability.

Significant efforts have been and continue to be made since the Fund's inception, to ensure that all New Jersey families are aware of the Fund's existence.

### Testimonials

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

*“Thank you so much for your time and guidance to assist our daughter with such a generous award. It feels wonderful to get caught up in our monetary responsibilities. Thanks again for all your kindness, patience and assistance.”* (Atlantic County parents of a 17-year-old).

*“We don’t know what we would have done without CICRFC. Our daughter is doing so much better now, back at school and making friends. Thanks again.”* (Camden County parents of a 16-year-old)

*“We really appreciate the good work that your office does. I don’t think we would be able to make his life as comfortable as it is, if it weren’t for you.”* (Monmouth County parents of 14-year-old)

*“From day one when we called the Catastrophic Illness in Children Relief fund, we felt HOPE, we felt so much concern about our situation, so much courtesy, so much respect, and most importantly, such genuine desire to help. I want to express our enormous gratitude to the Catastrophic Illness in Children Relief Fund Commission for the help, for giving us the hope of regaining confidence in our future, for making us feel that we are not alone in this world!”* (Essex County parents of an 18-year-old)

*“It is difficult to put into words how grateful we are for your financial support. The last few years for our family have been extremely trying. Your Fund’s financial reimbursement for our medical expenses have been a saving grace and will afford us the ability to stay in our home.”* (Bergen County parents of a 6-year-old)

*“My son will be a year old soon, and he is doing very well now. He is a joyful little boy. The joy he has brought to our family has been inexpressible. We live in a society where many believe they are owed something, not so with my wife and I. We understand that this gift from the Catastrophic Illness in Children Relief Fund was a gracious one and we thank you for it. We thank you from the bottom of our hearts we do not deserve anything, but you have given us so much ...you made our family much happier and increased the joy we now have.”* (Bergen County parents of a 1-year-old)

### Conclusion

Any family in New Jersey may find needed financial assistance from the Catastrophic Illness in Children Relief Fund if their child's uncovered medical expenses 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'10 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.

## 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.

### § 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.

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

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

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

L. 1987, c. 370, § 5.

**§ 26:2-153. Officers; quorum**

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

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

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

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

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

**§ 26:2-154. Powers; duties**

The commission has, but is not limited to, the following powers and duties:

- a. Establish in conjunction with the Special Child Health Services program established pursuant to P.L. 1948, c. 444 (C. 26:1A-2 et seq.) a program for the purposes of this act, administer the fund and authorize the payment or reimbursement of the medical expenses of children with catastrophic illnesses;

- b. Establish procedures for application to the program, determining the eligibility for the payment or reimbursement of medical expenses for each child, and processing fund awards and appeals. The commission shall also establish procedures to provide that, in the case of an illness or condition for which the family, after receiving assistance pursuant to this act, recovers damages for the child's medical expenses pursuant to a settlement or judgment in a legal action, the family shall reimburse the fund for the amount of assistance received, or that portion thereof covered by the amount of the damages less the expense of recovery;
- c. Establish the amount of reimbursement for the medical expenses of each child using a sliding fee scale based on a family's ability to pay for medical expenses which takes into account family size, family income and assets and family medical expenses and adjust the financial eligibility criteria established pursuant to subsection a. of section 2 of this act based upon the moneys available in the fund;
- d. Disseminate information on the fund and the program to the public;
- e. Adopt bylaws for the regulation of its affairs and the conduct of its business, adopt an official seal and alter the same at pleasure, maintain an office at the place within the State as it may designate, and sue and be sued in its own name;
- f. Appoint, retain or employ staff, experts or consultants on a contract basis or otherwise, who are deemed necessary, and employ investigators or other professionally qualified personnel who may be in the 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 child who is a resident of this State is eligible, through his parent or legal guardian, to apply to the program established pursuant to subsection a. of section 7 of this act.

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

**§ 26:2-156. Financial assistance**

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

L. 1987, c. 370, § 9; amended 1998, c. 143, § 5, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998; 2003, c. 260, § 3, eff. Jan. 14, 2004.

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

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

L. 1987, c. 370, § 10; amended 2007, c. 342, § 2, eff. Jan. 13, 2008.

**§ 26:2-158. Rules, regulations**

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

L. 1987, c. 370, § 11.

**§ 26:2-159. Annual reports**

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

L. 1987, c. 370, § 12; amended 1998, c. 143, § 6, eff. Dec. 21, 1998, retroactive to Jan. 1, 1998.

## Regulations

### § 10:155-1.1 Purpose and scope

- (a) The purpose of this subchapter is to establish criteria for eligibility and establish a standard methodology for determining the amount of financial assistance to be allocated for services of a child's health providers and vendors for families in the State of New Jersey whose child suffers from a catastrophic illness.
- (b) The procedures established shall be followed by the Catastrophic Illness in Children Relief Fund Commission.

### § 10:155-1.2 Definitions

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

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

“Batch” means a grouping of applications for the purpose of applying the provisions of N.J.A.C. 10:155-1.6, 1.7 and 1.8.

“Catastrophic Fund” or “Fund” means the Catastrophic Illness in Children Relief Fund.

“Catastrophic illness” means any illness or condition for which the incurred medical expenses not covered by any other State or Federal program or any other insurance contract or trust which allows funds to provide for the medically related needs of a child as defined in N.J.A.C. 10:155-1.14 or settlement relative to the medical condition of a child exceed 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000.

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

“Child” means a person 21 years of age and under.

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

“Days” means calendar days.

“Eligibility standard” means that dollar amount greater than 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000.

“Executive director” means the professional employed by the Commission, in accordance with NJ Department of Personnel’s procedures, to administer the Fund on a day-to-day basis on behalf of the Commission.

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

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

“Health insurance” means contracts, excluding automobile insurance contracts, whereby an insurer is obligated to pay or allow a benefit for the child as a named insured due to bodily injury, disablement, sickness, or because of any expense relating thereto or because of expense incurred in the prevention of sickness to include limited scope plans such as dental, vision, and prescription drug.

“Income” means the following:

1. Wages before deductions;
2. Public Assistance;
3. Social Security Benefits;
4. Supplemental Security Income;
5. Unemployment and Workman’s Compensation;
6. Strike Benefits from Union Funds;
7. Veteran’s Benefits;
8. Training Stipends;
9. Alimony;
10. Child Support;
11. Military Family Allotment;
12. Regular Support from Absent Family Member;
13. Pension Payments;
14. Insurance or Annuity Payments;
15. Income from Estates and Trusts;
16. Dividends;
17. Interest Income;
18. Rental Income;
19. Royalties; and
20. Other sources of income not mentioned above; however,
21. Income does not include the following money receipts: withdrawals from a bank; sale of property, house or car; tax refunds; gifts; one-time insurance payments; or compensation from injury, unless the injury directly relates to a child’s condition which is the basis for an application being made to the Fund. Also disregarded is non-cash income and any money raised by fundraising.

“Local agency” means the agency responsible for assisting families in the application process, forwarding applications to the State Office, and making appropriate referrals to other state programs and benefits.

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

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

#### § 10:155-1.3 General requirements

Pursuant to the Act, the Fund will provide assistance to families having a child with a catastrophic illness. A child shall have passed the initial screen for eligibility for the Fund’s assistance when a child’s incurred and verified medical expenses as specified in this chapter for a prior consecutive 12-month period exceed the amount represented by 10 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 residents in New Jersey are excluded from eligibility. Seasonal or temporary residence within the State, of whatever duration, does not constitute domicile. Migrant workers who can document a previous history of work in New Jersey are eligible for consideration.

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

Applications may be submitted on a year-round basis to the local agency. The name, address, and phone number for the local agencies shall be available from the State Office. The local agency shall forward written applications on forms provided by the State Office for those children who have applied to the State Office.

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

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

### § 10:155-1.6 Eligibility standard

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

### § 10:155-1.7 Annual caps and vehicle allowance; home modification allowance; speech, language and hearing allowance; applied behavioral analysis allowance

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

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

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

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

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

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

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

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

(a) The State office shall:

1. Screen applications to determine whether a child's eligible medical expenses exceed 10 percent of the first \$100,000 of annual income of a family plus 15 percent of the excess income over \$100,000;
2. Maintain oversight to the local agency responsible for assisting families with Program, accepting applications and providing local outreach/information;
3. Administer the Fund on a day-to-day basis on behalf of the Commission;
4. Monitor providers eligibility (that is, certification or other credentials);
5. Consider the reasonableness of providers and vendor charges;
6. Prepare applications for review and consideration of the Commission; and
7. Oversee payments to providers, vendors and, in some cases, to families.

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

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

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

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

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

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

(a) Categories of incurred health expenses which are medically-authorized in the care of a child with an illness or condition eligible for consideration is assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$100,000 include, but are not limited to, the following:

1. Physician-authorized ancillaries (labs, x-rays);
2. Specialized pediatric ambulatory care, including physician-authorized rehabilitative therapies (for example, speech, occupational, and physical), physician-authorized care for treatment of addiction disorders and mental health care, dental care, eye care, chiropractic care;

3. Care in an acute hospital in New Jersey (treatment for acute and chronic conditions and treatment of addiction disorders and mental health conditions);
  4. Care in acute hospitals in other states (treatment for acute and chronic conditions, and treatment of addiction disorders and mental health conditions as well as highly specialized care such as organ transplants);
  5. Physicians and nursing services in all settings, including primary care (preventive care) and immunization services (for example, office, hospital);
  6. Care in specialty hospitals (for example, rehabilitative, psychiatric);
  7. Long term care (respite care, hospice care, residential care, or other care);
  8. Home health care (physician-authorized home health aide, physician-authorized public health nurse, physician-authorized private duty nurse or other care);
  9. Pharmaceuticals (physician-authorized Federal Drug Administration approved over-the-counter and prescription drugs related to the medical condition and physician-authorized Federal Drug Administration approved medical formulas);
  10. Disposable medical supplies (physician-authorized over-the-counter and prescribed supplies);
  11. Durable medical equipment (for example, physician-authorized ventilators, prostheses);
  12. Home modification that is related to the medical condition of the child at the time the expenses were incurred;
  13. Purchase of a specialized leased or specialized, modified vehicle and any subsequent modifications that are related to the medical condition of the child at the time the expenses were incurred; and
  14. Experimental medical treatment/experimental drugs which are recognized by Federal or State agencies and provided by licensed health care providers. Applications involving experimental treatment/experimental drugs may require additional review.
- (b) Categories of incurred health-related expenses are eligible for consideration in assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 include:
1. Family transportation and travel-related expenses including, but not limited to, mileage allowance, tolls, parking receipts, temporary shelter costs and telephone calls related to medical condition.
- (c) Fifty percent of a health insurance premium including supplemental and dependent coverage that is paid by a family, not to exceed 50 percent of total eligible expenses, when accompanied by eligible expenses in (a) or (b) above.

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

Categories of health and health-related expenses which are not eligible for consideration in assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 shall include, but are not limited to, the following:

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

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

- (a) The State Office shall oversee processing of payments from the Fund. Though in general payments shall be made directly to providers and vendors, consideration shall be given to making payments directly to families.
- (b) Items in N.J.A.C. 10:155-1.14, Eligible health services, shall be considered for payments.
- (c) For the purpose of providing the moneys necessary to establish and meet the purposes of the Fund, the Commission shall establish a \$ 1.50 annual surcharge per employee for all employers who are subject to the New Jersey “Unemployment Compensation Law,” N.J.S.A. 43:21-1 et seq. The surcharge shall be collected by the Controller for the New Jersey Unemployment Compensation Fund and paid over to the State Treasurer for deposit in the Fund annually as provided by the Commission.

**§ 10:155-1.17 Appeal process**

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

New Jersey State Department of Human Services  
Catastrophic Illness in Children Relief Fund Commission  
PO Box 0728  
Trenton, NJ 08625-0728  
Attn: Chairperson
  - 2. Appeals must be received at the above address no later than 30 days from the date of notice of the determination made by the State Office. The Commission may waive the deadline for cause.
  - 3. The written appeal shall include all reasons and grounds for disputing the determination made by the State Office and all proof and documentation in support of the appeal.
  - 4. The Commission shall conduct such review and analysis as is necessary to reach a decision on the appeal. At its discretion, the Commission may direct a conference to be convened with the applicant, or may refer the matter to the Office of Administrative law pursuant to the Administrative Procedure Act, N.J.S.A. 52:14 B-1 et seq., and the Uniform Administrative Procedure Rules, N.J.A.C. 1:1.
  - 5. Except for appeals referred to the Office of Administrative Law, the Commission shall render a decision on the appeal within 180 days from the date of original receipt of the appeal. Appeals referred to the Office of Administrative Law shall be decided by the Commission within 45 days from the date of filing of the Initial Decision of the Administrative Law Judge, or at such later date as permitted by law.
  - 6. A decision made by the Commission shall be final. It may be appealed to the Superior Court of New Jersey as permitted by court rules.
- (b) Unless otherwise specifically ordered by the Commission, an applicant may not receive benefits from the Catastrophic Illness in Children Relief Fund while an appeal is pending at any level.

**§ 10:155-1.18 Special cases**

- (a) Special cases shall be referred to the Commission for its review and consideration. Special cases shall include, but are not limited to, the following:
1. In special cases in which a family has more than one child with a catastrophic illness (as defined by expenses in excess of the 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000 threshold for each child), consideration shall be given to waiving the family responsibility as outlined in N.J.A.C. 10:155-1.2 for the other child/children given that the family would have already met the family responsibility for the first child in a State fiscal year.
  2. For special hardship cases that come before the Commission during a batch cycle, after the standard disbursement guidelines have been applied to each case in the batch and sufficient monies remain in the Fund, consideration shall be given to waiving the standard disbursement guidelines (that is, the family responsibility and the caps outlined in N.J.A.C. 10:155-1.2 and 1.7).

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

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

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

- (a) If a family receives assistance from the Fund for a child, in accordance with this chapter, and subsequently recovers damages or a financial award for the child's medical expenses, pursuant to a settlement or judgment in a legal action, the family shall reimburse the Fund for either:
1. The amount of assistance received from the Fund; or
  2. The portion of assistance received for the injury, illness or condition covered by the damage or judgment, less the family's expenses of recovery.
- (b) The Commission may negotiate or settle the recovery of such claims, for cause presented by the family to the Commission.

**Examples of Catastrophic Illness in Children Relief Fund Program\*:**

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

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

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

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

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

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

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

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



## **Catastrophic Illness in Children Relief Fund**

**Chris Christie, Governor**

Kim Guadagno, Lieutenant Governor

Jennifer Velez, Commissioner of Human Services

Jane Schreadley Lorber, CICRF Chairperson

Claudia L. Marchese, Esq., CICRF Executive Director