

The Catastrophic Illness in Children Relief Fund

When other resources end, we begin.

The Catastrophic Illness in Children Relief Fund

Annual Report: FY 2006 - 2008



A NEW SENSE OF HOPE WHEN YOU NEED IT MOST.

**Catastrophic Illness in Children Relief Fund
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LETTER FROM THE COMMISSION CO-CHAIRS

July 2009

On behalf of our fellow Commissioners, we are pleased to provide this combined annual report for Fiscal Years 2006-2008.

The Catastrophic Illness in Children Relief Fund (CICRF) continues to support some of the most vulnerable children in Massachusetts. In 2008, the Fund completed its eighth year of providing critical assistance to families. We are very proud of the work we do, as one of only a few Funds of this kind in the nation. Through the work of our Commissioners, and supported by the excellent staff at the Department of Public Health (DPH), we have served over 750 children (through FY08) from all across the state.

The Fund provides critical financial support to families struggling to care for children with extensive medical needs. This financial support can make an enormous difference in a family's day-to-day life and financial stability. In many instances, the Fund "fills the gaps" left by traditional insurance coverage, helping families afford specialized equipment, providing transportation resources, and assisting with home and vehicle modifications for children with mobility impairments. The testimonials of parents found throughout this report speak to the remarkable differences we have made in children's lives.

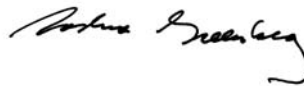
While this report summarizes Fiscal Years 2006-2008, it is worth noting that the upcoming Fiscal Year 2009 report will show an even greater need for the financial support the Fund provides to families of children with special health care needs. Fiscal Year 2009 saw a significant increase in applications to the Fund, and, given economic projections, similar increases are expected over the next few years. Families across the Commonwealth are in severe financial crisis. As families lose employment earnings and other sources of funding assistance dwindle, the CICRF has become an even more critical resource for families of children with special health care needs.

We welcome your comments, feedback and ideas as we seek to improve our ability to serve children and families.

Yours truly,



Patricia Roche, M.Ed., J.D.
Co-Chair



Joshua Greenberg, J.D.
Co-Chair

EXECUTIVE SUMMARY

Purpose of the Fund

The Catastrophic Illness in Children Relief Fund (CICRF) was established by legislation for FY 2001. The purpose of the Fund is to provide assistance to families for catastrophic medical and medically related expenses that are not covered by any insurer or other program.

From the Fund's inception through FY 2008, it has provided \$9.9M in reimbursements to the families of 766 children with catastrophic illnesses, from a variety of backgrounds. Massachusetts families with children under 22 years of age, whose medical and related expenses for one child exceed 10% of the first \$100,000 plus 15% thereafter of the family's annual income, are eligible to apply for assistance from the CICRF.

Fiscal Years 2006-08 Summary

- During FY06-08, 456 families received a total of \$4.3 M in reimbursements.
- 187 families received a total of \$1.4 M in reimbursements in FY06; 139 families received a total of \$1.2 M in FY07; and 211 families received a total of \$1.7 M in FY08.
- The number of applications to the Fund has grown significantly each year, with 187 applications submitted in FY06, 242 in FY07, and 330 in FY08. First-time applicants represent approximately 71% of applications each year.
- The children who have been assisted by the CICRF have a variety of different diagnoses, typically come from low-income families, and almost all have some form of health insurance coverage. Most notably, during FY06-08, approximately 60% of the families who received assistance had annual incomes of less than 200% of the federal poverty level (\$42,000 for a family of 4 in 2008), and approximately 43% of the children who were helped during this period were under the age of five.
- The CICRF supports a wide variety of services, including medical equipment, medical services, hospital and physician services, medications, family support, and home and vehicle modifications that enable children to remain at home and a part of their communities, rather than in residential or institutional care.
- In addition to providing financial assistance to families, the Fund provides families with information, referrals and technical assistance related to accessing other financial and other supports. As a result, many families who have been determined ineligible for the Fund due to the financial criteria have received other types of support and assistance from the Fund.
- In February 2006, a celebration of the first five years of the Fund was held at the State House. A number of families that have been assisted by the Fund attended the event and attested to the benefits that such a fund can provide.
- Legislation expanded age eligibility for the Fund from 18 to 21 years of age beginning FY07.
- In FY08 the Fund underwent an independent state audit, which found Fund expenditures to be appropriate, reasonable and in compliance with applicable laws, rules and regulations.

TABLE OF CONTENTS

Letter from the Commission Co-Chairs	i
Executive Summary	ii
Table of Contents	iii
I. Introduction.....	1
II. Catastrophic Illness in Children Relief Fund Program	2
Eligibility	2
Eligible Services	2
Commission Responsibilities.....	3
III.Data	4
Fund Accomplishments and Highlights.....	4
Applications Received in Fiscal Years 2006-08.....	4
Families Receiving Financial Assistance in Fiscal Years 2006-08	5
Diagnoses.....	5
Geography.....	7
Age.....	8
Income Level	9
Insurance Status	10
Services Supported.....	11
Reimbursements to Families.....	13
IV. Revenue and Expenditures.....	15
V. Conclusion	16
Commission Member List	17

I. INTRODUCTION

The Catastrophic Illness in Children Relief Fund (CICRF) was established by state legislation in July 2000 to help families bear the excessive financial burdens associated with the care of children with high medical and related expenses. It provides last resort financial assistance for families in Massachusetts that are struggling to pay for medical or medically-related expenses not covered by a private insurer, federal or state health care assistance, or any other financial source. Since FY 2001, the Fund has served hundreds of families from across Massachusetts, providing basic support to allow children to remain at home and be cared for in their communities.

The CICRF was established within the Department of Public Health, in accordance with the Massachusetts General Laws, Chapter 29, Section 2ZZ, and administered by the CICRF Commission, which was established and is governed by Chapter 111K of the Massachusetts General Laws. A catastrophic illness is defined as “any illness or condition treated at a pediatric specialty hospital, including ambulatory care and services provided by or ordered through such a hospital, the medical and related expenses of which are not covered by any other state or federal program...or any insurance contract and which exceed 10 percent of the first \$100,000 of annual income of a family and 15 percent of any family income in excess of \$100,000.” Originally created for families of children ages 18 and under, in FY07 Chapter 111K was amended to expand age eligibility for the Fund through age 21.

The Fund is overseen by a Commission consisting of 11 members (4 state agency ex-officio members and 7 public members), and is staffed by the Department of Public Health. The Fund is financed by quarterly transfers from the Medical Security Trust Fund, if sufficient funds are available. (See section IV for more detailed information about the funding of the CICRF.)

From its inception through FY08, the CICRF has provided funds to **766** children with a wide array of medical conditions and diagnoses. Their families come from across the state, from all income levels, and are largely insured either through private coverage and/or MassHealth. Families have been reimbursed for a variety of eligible expenses, including hospital and physician services; medication; medical equipment and supplies; travel and lodging; funeral expenses; special therapies; accessible vehicle purchases; home and vehicle modifications; and expenses incurred while caring for a sick child in the hospital.

The cost of caring for a chronically ill child can be overwhelming, even to a family with health insurance. High insurance premiums, deductibles and co-payments, combined with medical and medically related expenses incurred because of coverage limitations and exclusions, can result in a serious drain of a family’s financial resources. The bills acquired can send the family into extreme debt and cause severe emotional stress. In fact, studies have shown that the leading cause of personal bankruptcy in the U.S. is medical bills resulting from an illness (even with health insurance coverage). One study

showed that sixty-one percent of these families in a “medical” bankruptcy went without needed medical care.¹

The impact of a child’s illness can have severe ripple effects. The time and energy necessary to care for a sick child often place further debilitating strain on a family and often results in loss of employment of one or both parents. In such situations, the family loses not only income, but frequently loses health benefits as well (since access to health insurance is often through one’s employer). The sick child then may be uninsured for some period of time, or the family has the additional burden of affording the full cost of insurance premiums. There are also many expenses resulting from a child’s medical condition that are not covered by insurance. The CICRF thus provides valuable or stabilizing financial and emotional relief for families facing incredible life challenges.

“I want to express to you the sincere joy and relief the CICRF has given me as a parent with a child with extensive medical needs. I am grateful in knowing that there is an organization that understands the overwhelming struggles of having a child with medical issues and has ensured funding is available to assist those in need. You have blessed us with giving my son the opportunity of having medical treatments that he would have been otherwise unable to receive.”

-Recipient Family

II. CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND PROGRAM

Eligibility

In order for a family to be eligible for assistance, they must have a child who:

- Is 21 years of age or younger²
- Is a Massachusetts resident
- Is under the care of a licensed health care provider who has staff privileges at a hospital which is licensed or accredited to provide pediatric or neonatal care
- Has catastrophic medical or related expenses (defined as annual out-of-pocket expenses totaling more than 10% of the first \$100,000 of the family’s income plus 15% of any income in excess of \$100,000, after all other avenues of reimbursement have been exhausted)

Eligible Services

The CICRF has a strong bias toward helping children to remain at home in their communities. It therefore considers reimbursement to families for a broad range of

¹ D.U. Himmelstein, E. Warren, D. Thorne, S. Woolhandler. Market Watch: Illness and Injury as Contributors to Bankruptcy. Health Affairs – Web Exclusive. 2005 Feb 2; W5: 63-73. Epub 2005 Feb. 2.

² Age eligibility was increased from 18 to 21 years of age or under as part of Chapter 139 of the Acts of 2006, effective July 1, 2006.

medical and related services and expenses that may not be reimbursable under traditional health insurance policies, or for which the family does not have coverage, including but not limited to:

- Physician's expenses
- Specialized pediatric ambulatory care (testing, laboratory work, etc.)
- Acute or specialized hospital care, both inpatient and outpatient
- Rehabilitative therapies
- Medical equipment and supplies
- Medications
- Medically related home and vehicle modifications
- Health enabling services and equipment
- Related travel expenses such as mileage and lodging
- Funeral expenses
- Insurance co-payments and deductibles
- CommonHealth and MassHealth premiums

Following a special review, experimental treatment or medications, assistive technology, alternative or complementary treatment, home health care and other medically related services may be considered for reimbursement.

Generally families that apply to the Fund seek assistance with multiple expenses. As a payer of last resort, private and public insurance coverage is sought first. Some reimbursements reflect partial payments for medical and related services, such as co-payments and deductibles for physician visits, hospitalizations, medications, and rehabilitation therapies.

Commission Responsibilities

The CICRF Commission consists of eleven (11) members, including [designees of] the Secretary of Health and Human Services, the Commissioner of Public Health, the Commissioner of Insurance, the State Treasurer and seven public members (including a representative of the AFL-CIO and at least two providers of health care services to children in Massachusetts). The Commission is responsible for establishing the policies and procedures necessary for administration of the CICRF, including application to the Fund, application review, determination of eligibility for services, and reimbursement.

The Department of Public Health (DPH) is responsible for the general management and administration of the program, including maintaining confidential records for each child, determining eligibility and the amount of reimbursement, and preparing application or case materials for review by the entire Commission. **The Commission's goal is to act in the best interest of the child while ensuring that the Fund remains the payor of last resort.** Department of Public Health staff devote significant resources to case management and referral activities. If, upon review of an application, the applicant is found to be potentially eligible for funding through other sources or programs, DPH staff assist the applicant in applying for alternate benefits and resources.

III. DATA

Fund Accomplishments and Highlights

From the establishment of the CICRF in FY01 through FY08, the Fund has provided \$9.9M in reimbursements to 766 Massachusetts families with catastrophic medical or related expenses. It has proven to be an invaluable resource for families struggling with the need to preserve family life in the face of unbearable financial obligations. The Fund has assisted families from a variety of income levels with a wide range of awards in proportion to their need.

Payments to an individual family for FY06, FY07 or FY08 ranged from a low of \$6.48 to a high of \$43,975.00³. Some families have been eligible to receive CICRF assistance over multiple fiscal years.

In February 2006, a celebration of the first five years of the Fund was held at the State House. A number of families that have been assisted by the Fund attended the event and attested to the benefits that such a fund can provide.

The Fund, under the leadership of its experienced co-chairs and with broad legislative support, generated several significant changes during this reporting period. This included an increase in age eligibility from 18 to 21 years of age, as well as an increase in the cap on administrative expenditures from 3% to 5% of annual transfers. This was significant, as it allowed for hiring of an additional staff person to do outreach and review applications, and thereby assist more families in need.

Applications Received in Fiscal Years 2006-08

The number of applications submitted to the Fund has increased significantly in each of the three years covered by this report. During this period, the Commission and staff made a concerted effort to increase outreach efforts to families across the Commonwealth. Fund staff made numerous presentations and met with potential referral sources and family groups in order to increase awareness about CICRF. These efforts continue.

From FY01 through FY08, 1,457 applications have been submitted to the CICRF. Table 1 shows the number of applications submitted in FY06, 07 and 08. Of note is the increase in the number of applications submitted each year. The number of first-time applicants exceeded 70% of the total each year. This is very encouraging, as it indicates that more families are aware of the help the Fund can provide, and the increase in applications is not simply a result of the same families re-applying year after year.

³ For some families, a majority of the reimbursements were received in a prior fiscal year. For others, payment in FY06, FY07 or FY08 could include expenses incurred over several years.

TABLE 1: Applications Submitted

	FY06	FY07	FY08
First-time applicants	131	173	239
Re-applicants (first application received in a previous year or earlier that year)	56	69	91
TOTAL applications	187	242	330
% of applications received that were from families applying for the first time	70.1%	71.5%	72.4%

Families Receiving Financial Assistance in Fiscal Years 2006-08

This report focuses on the families that received reimbursement in FY06 (187 families), FY07 (139 families), and/or FY08 (211 families).

Due to the timing of receipt of applications and the documentation required to determine a family eligible for reimbursement, applications may be received in one fiscal year and associated reimbursements may not occur until the following fiscal year. Note that the fact that the same number of families (187) applied to the Fund in FY06 and received reimbursement from the Fund that year is purely coincidental; while there is significant overlap, they are not the identical group of families.

Some families may receive payments over multiple fiscal years, due to the submission of reapplications and/or one application resulting in multiple payments over time. The (unduplicated) number of families who received financial assistance from CICRF in FY06-08 is 456.

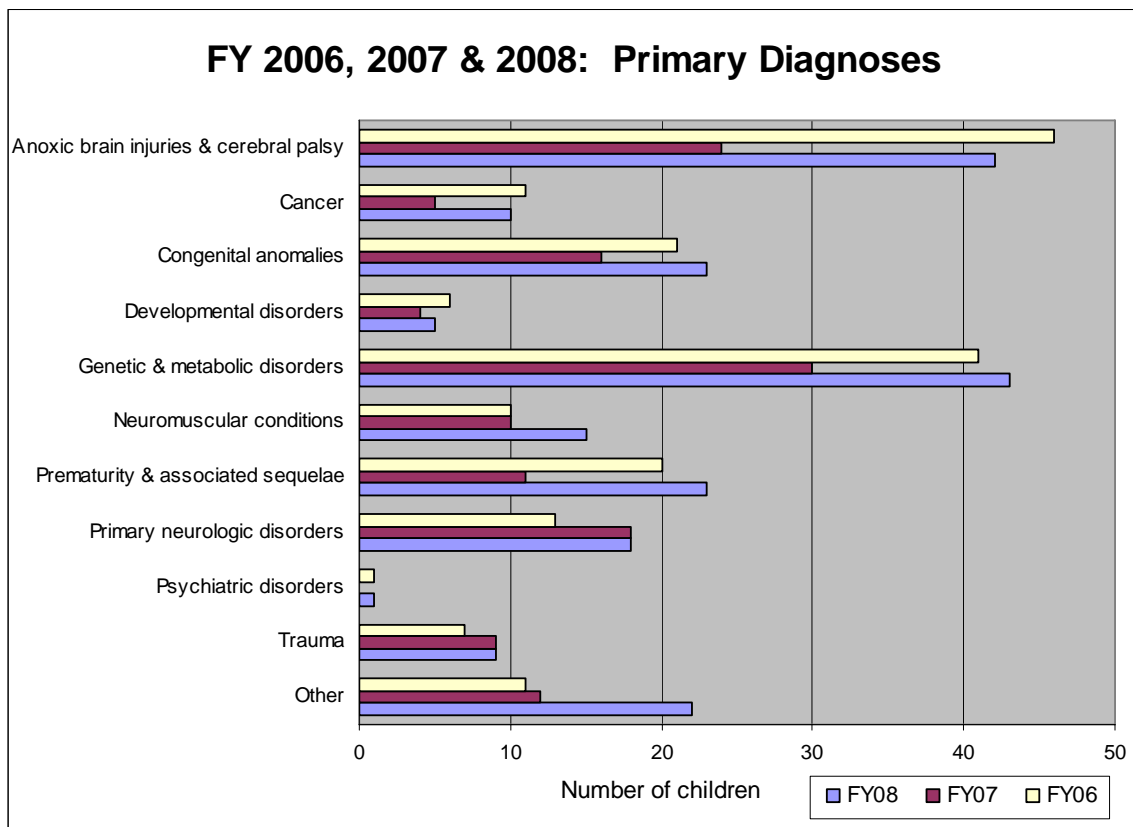
Unless otherwise indicated, the data below are based on families who have received financial assistance from the Fund (“families served”).

Diagnoses

The CICRF provides support for children with a wide variety of serious medical conditions. The broad categories of diagnoses of CICRF applicants include anoxic brain injuries and cerebral palsy; neuromuscular conditions (such as muscular dystrophy); genetic and metabolic conditions; cancers; primary neurologic disorders; developmental disorders; psychiatric disorders; prematurity and associated sequelae; and traumatic injuries. Most of these diagnoses have a number of associated conditions that dramatically impact the lives of the children who have them. Examples of associated conditions include seizure disorders, vision and hearing loss, incontinence, respiratory conditions, and inability to eat safely by mouth. Oftentimes children with these challenges are entirely dependent on others for aspects of daily living, such as getting

dressed, toileting, or even rolling over in bed. Many use wheelchairs or have substantial mobility impairments. The scope of impact of these medical conditions on the quality of life of the children and families who apply for support from CICRF cannot be overstated.

The chart⁴ below portrays the variety of conditions of the children assisted by the CICRF in FY06-08. The largest categories of conditions for which the Fund provided children and their families with support are anoxic brain injuries and cerebral palsy; genetic and metabolic disorders; congenital anomalies; and prematurity and associated sequelae.⁵ Many of the conditions are chronic and require significant, ongoing medical care and/or pharmaceutical regimens. Other conditions severely impact mobility, resulting in families' need to make their living space and modes of transportation accessible to the child, making it easier for them to live in the community.



NOTE: Comparisons to previous years' reports should not be made because changes have been made to the categories.

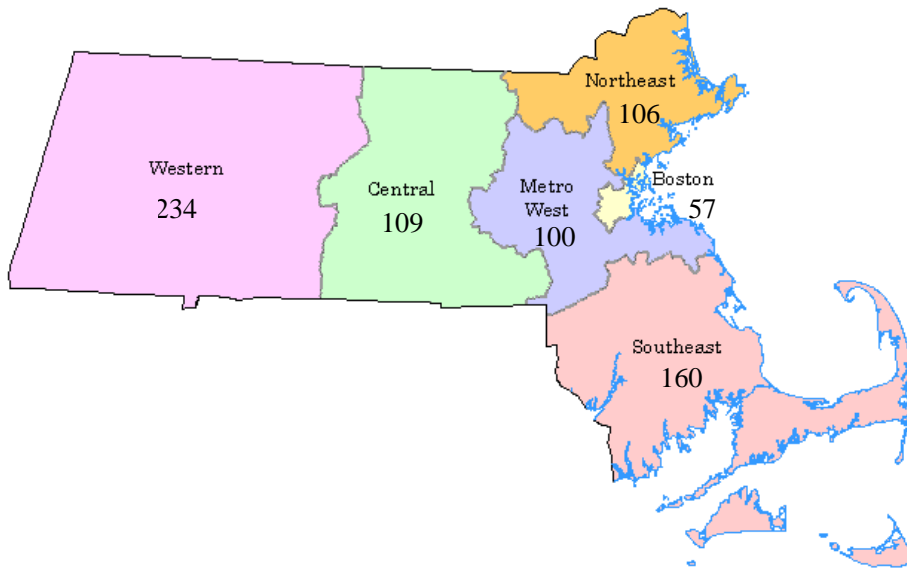
⁴ For all FY01-FY08 charts, the total number of children is 766; for combined FY06-08 charts, the total number of children is 456. For charts showing breakdown by year, the total number of children is 187 in FY06, 139 in FY07, and 210 children in FY08. The total exceeds 456 because some children received assistance in multiple years. All data are derived from the Massachusetts Department of Public Health Catastrophic Illness in Children Relief Fund database, 2009.

⁵ Many children assisted by the Fund had multiple diagnoses that would fit into multiple diagnostic categories. The chart above represents the child's primary diagnosis as identified by the family or as determined by Fund staff after a review of the application.

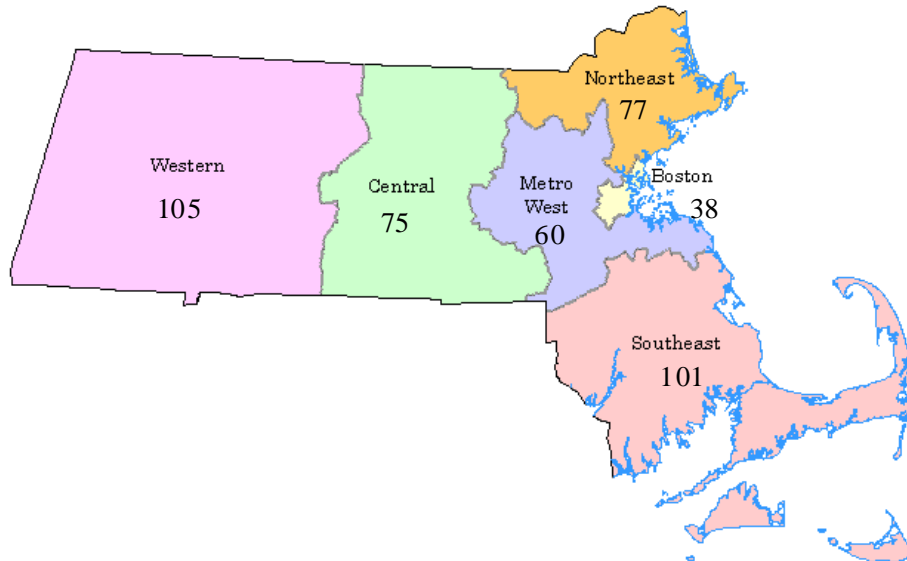
Geography

The CICRF serves children and families from across all regions of Massachusetts. Fund staff conducts outreach activities on an ongoing basis, as evidenced by the use of the CICRF's services in each of the Department of Public Health regions. The majority of the children served are located outside of the Greater Boston area, and often must travel to Boston to receive specialized care (a significant family expense when many visits or hospitalizations are required). The maps below show the number of families served in each region since the Fund's inception and for FY06-08, respectively.

**Families Served—Since Fund Inception
FY 2001-FY 2008**



Families Served—FY 2006-FY 2008



Age

Table 2 shows the breakdown of children's age at time of application for the children reimbursed in each year. The average age has remained fairly constant over time, at just over 7 years.

The percent of children served who are under 5 years of age has increased steadily each year (40% in FY05, 42% in FY06, 43% in FY07, and 45% in FY08). A significant percentage of children served are those under age 1. This is likely due to prematurity and/or medical concerns that result in a child remaining in the hospital for a lengthy period of time after birth. Many families apply to the Fund for assistance with costs associated with visiting their child in the hospital on a regular basis over an extended period of time.

FY07 saw the first families of children between the ages of 19 and 21 receiving assistance from the Fund. In Chapter 139 of the Acts of 2006 the legislature raised the age eligibility for the Fund from 18 to 21.

TABLE 2: Age of Children Receiving Reimbursement (at time application submitted)

Age Group	FY 2006		FY 2007		FY 2008	
	Number	Percent	Number	Percent	Number	Percent
Under age 1	32	17.1%	14	10.1%	32	15.2%
1 – 4 years	46	24.6%	46	33.1%	63	29.9%
5 – 9 years	52	27.8%	29	20.9%	47	22.3%
10 – 14 years	37	19.8%	36	25.9%	41	19.4%
15 – 18 years	20	10.7%	11	7.9%	25	11.8%
19 – 21 years	--	--	3	2.2%	3	1.4%
Total	187	100.0%	139	100.0%	211	100.0%
Average age	7.2 years		7.3 years		7.4 years	

Income Level

The majority of families helped by the CICRF are extremely low-income and have limited access to other resources. Often a family with a catastrophically ill child has large, immediate expenses, which, in conjunction with their low-income level, make traditional loans unavailable or unaffordable. For these families, the Fund represents a major and sometimes sole source of hope and support.

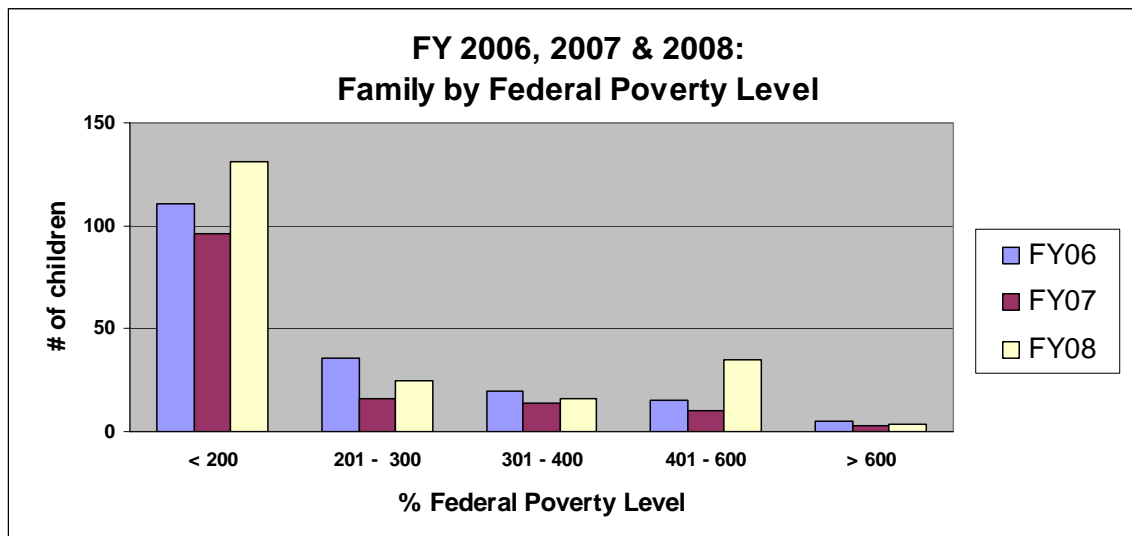
The CICRF provides assistance to families at all income levels as defined by the U.S. Department of Health and Human Services (USDHH). The federal poverty level (FPL) is

a measure of family income that is calculated each year by the USDHH. It is used to determine financial eligibility for a variety of programs. These guidelines are a simplified version of the “poverty thresholds” developed by the census bureau.⁶

In FY06-08, between 74% and 81% of families served per year had income less than 300% of FPL). This is noteworthy, since MassHealth eligibility for children extends to 300% FPL. In 2008, 300% FPL was \$63,600 for a family of four.

TABLE 3: Family Income, by Percent of Federal Poverty Level

Percent of FPL	FY 2006		FY 2007		FY 2008	
	Number	Percent	Number	Percent	Number	Percent
≤ 200%	111	59.4%	96	69.1%	131	62.1%
201-300%	36	19.3%	16	11.5%	25	11.8%
301-400%	20	10.7%	14	10.1%	16	7.6%
401-600%	15	8.0%	10	7.2%	35	16.6%
601-800%	5	2.7%	3	2.2%	3	1.4%
>800%	0	0.0%	0	2.2%	1	0.5%
Total	187	100.0%	139	100.0%	211	100.0%
Average income	\$ 40,696		\$ 37,561		\$ 43,572	
Median income	\$ 33,961		\$ 29,852		\$ 32,108	



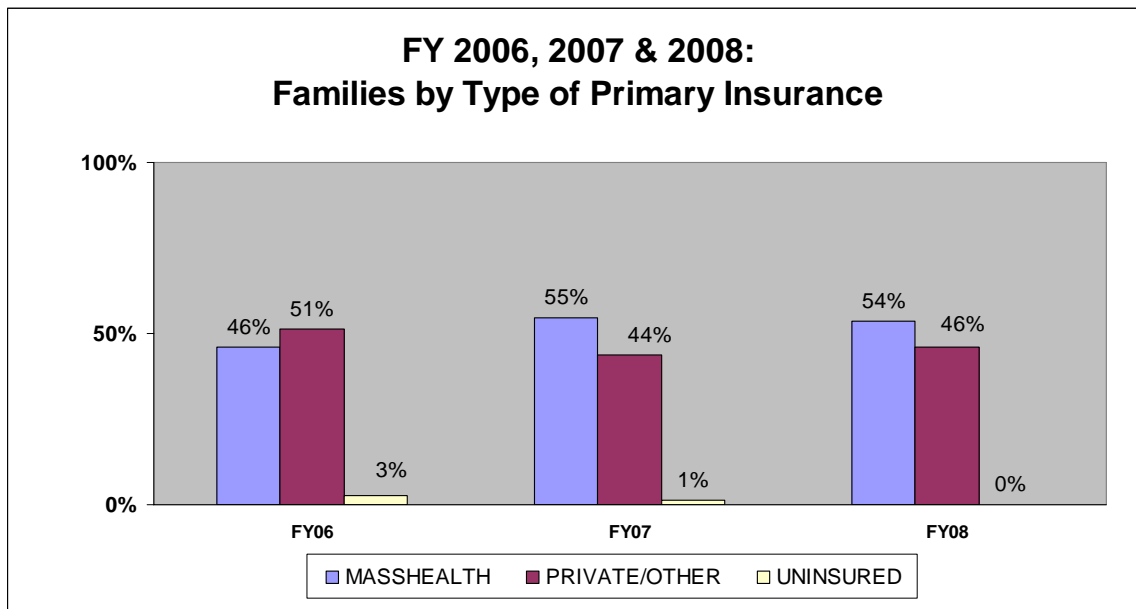
⁶ <http://aspe.hhs.gov/poverty/faq.shtml>, accessed June 18, 2009

Insurance Status

Almost all children assisted by the CICRF have health insurance (97% were insured in FY06; 99% in FY07; and 100% in FY08).⁷ Nevertheless these families still had catastrophic medical or related expenses, despite their coverage. Often this is because the insurance does not cover certain services or expenses, or because families have significant co-pays or deductibles associated with care. Other times, the expenses are so great that families reach benefit limits and are left to cope with the rest of the expenses themselves. Fund staff make every effort to ensure insurance is used first and the Fund is a payor of last resort.

The chart on the following page identifies the primary insurance coverage of the families that were reimbursed by the CICRF in FY06-08. In addition, most families with private insurance had secondary Medicaid or CommonHealth coverage in order to supplement their primary private insurance. In each year over 90% had MassHealth or CommonHealth as a primary or secondary insurer.

A small percentage of children included in the MassHealth category in the chart had MassHealth Limited (2% in FY06; 4% in FY07 and 3% in FY08). MassHealth Limited is emergency medical coverage for noncitizens who are not eligible for other MassHealth programs because of immigration status (but otherwise meet MassHealth income eligibility criteria). While most of those children were also covered by the Children's Medical Security Plan, which provides basic health coverage, these two plans alone do not meet all of the service, medication and equipment needs of children with chronic or complex medical needs.



⁷ If a family applies to the CICRF and staff learn that the child does not have health insurance, CICRF staff refers the family to the appropriate resource(s), to ensure all children have insurance coverage for which they are eligible.

Services Supported

The Fund reimburses families for a diverse set of medical and related services and expenses. Examples of eligible expenses include medical supplies and equipment, such as wheelchairs; physical, occupational, and speech therapy; hospital and physician services; per diem travel and related expenses during inpatient hospitalizations; and some alternative or complementary treatments (following an in-depth review by the Commission). Most families receive reimbursement from the Fund for more than one type of expense. Some expenditures reflect partial payments for medical and related services, such as co-payments and deductibles.

See the table and chart on the next page for the distribution.

The Commission supports families' decisions to care for their children in their homes. Financial support from the Fund allows many families to avoid residential or institutional care by enabling them to make structural or other modifications that are necessary in order to care for their child at home (such as an accessible bathroom or a wheelchair accessible home entrance/exit). The Fund also assists families that need an accessible vehicle to transport their child to medical visits within the community.⁸ The largest percent of funds reimbursed to families each year are for Family Support, which represents expenses parents incur while being with and caring for a sick child in the hospital or expenses incurred by lengthy outpatient appointments. Many children have multiple and/or lengthy hospitalizations – sometimes for many months at a time – and parental involvement as part of the child's care team at the hospital is critical to the child's care, making this support essential.

As children grow, their needs change, and this has been reflected in some of the requests received by the Fund in recent years. The Commission has begun to receive repeat requests from families who were assisted in earlier years of the Fund. In particular, as children get older they outgrow certain equipment, such as leg braces and wheelchairs, which require replacement or modification in order to continue to meet the child's needs. Parents who may have been able to lift their child into a vehicle when the child was smaller may now require a wheelchair lift. Also, equipment simply wears out over time. For example, an eight year old wheelchair accessible van may no longer be roadworthy and may need to be replaced.

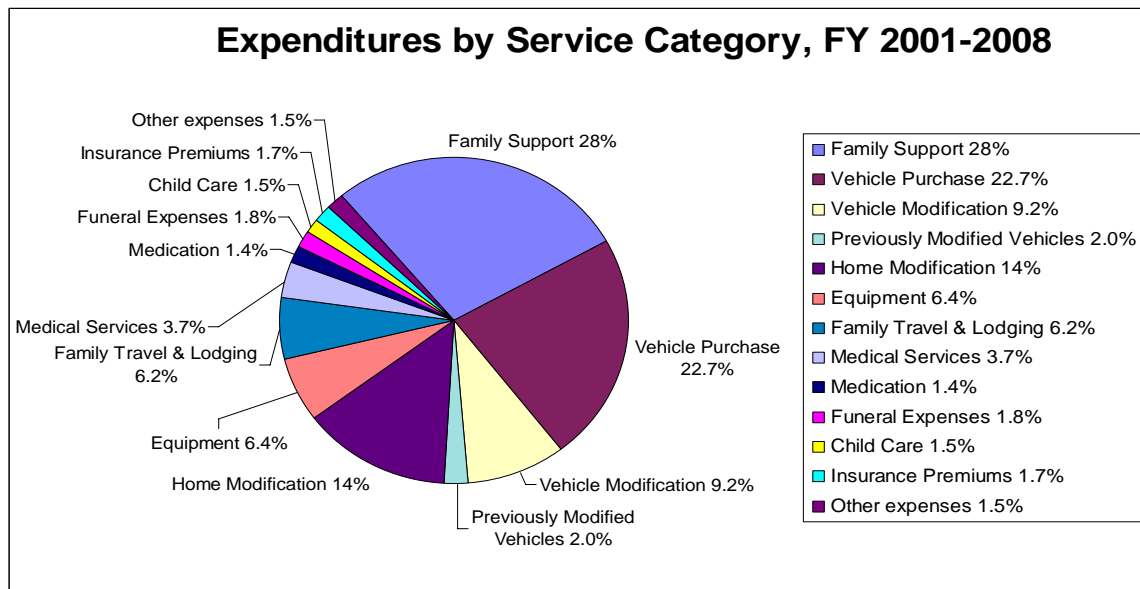
“Thank you so much for your kind understanding and generosity. Having to deal with all these medical issues has definitely taken a toll on us. Thanks to the Fund, we have been able to keep our house and pay many overdue bills.”

-Recipient Family

⁸ Certain expenses, such as home and vehicle modifications, are reimbursed according to a sliding scale, and families have a lifetime limit on the number of these types of projects for which the Fund will reimburse.

TABLE 4: Expenditures by Service Category

Service Category	FY06	FY07	FY08
	Percent of total expenditures	Percent of total expenditures	Percent of total expenditures
Family support	27.3%	40.7%	37.4%
Vehicle purchase	24.3%	22.1%	20.7%
Vehicle modification	10.4%	7.8%	6.7%
Previously modified vehicles	4.8%	2.8%	5.8%
Home modification	10.7%	12.2%	13.4%
Equipment	7.4%	3.9%	5.3%
Funeral expenses	2.0%	1.7%	2.8%
Child care	1.5%	3.9%	2.6%
Family travel & lodging	3.0%	0.9%	2.1%
Medical services	3.8%	1.6%	1.1%
Medication	2.3%	0.9%	0.6%
Insurance premiums	1.8%	0.3%	0.6%
Other	1.0%	1.3%	1.0%
Total Expenditures	\$ 1,437,729	\$ 1,180,503	\$ 1,699,298



“Thank you for your continued support for allowing my child to reach her full potential! She is doing amazingly well since her return from her therapeutic program...These successes have only been possible through CICRF, by allowing us to focus on our child’s needs and the financial setbacks of her condition. Thank you again for contributing to our daughter’s success.”

- Recipient Family

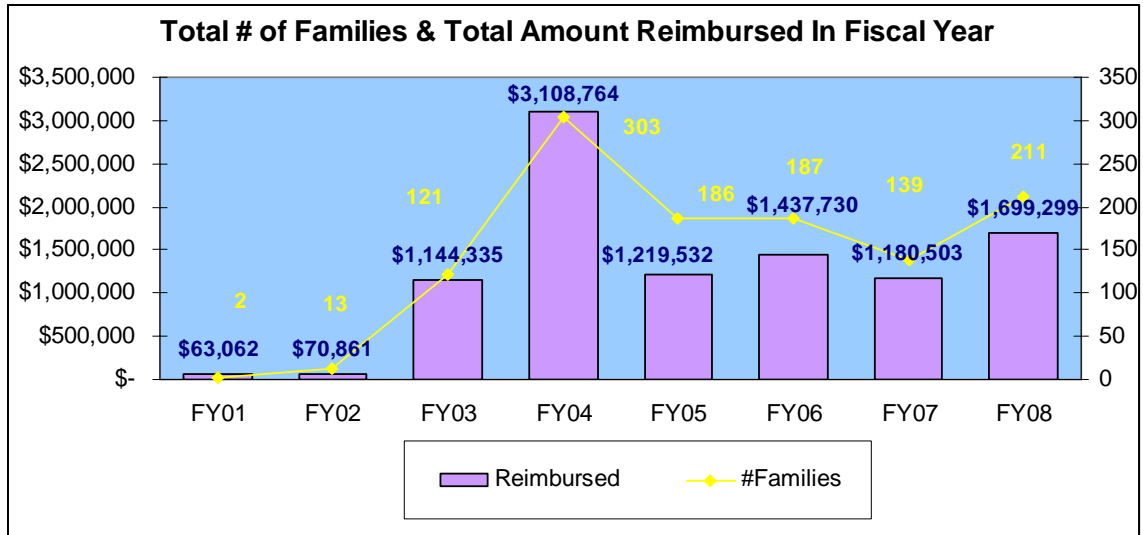
Reimbursements to Families

Total reimbursements to families in FY06 increased slightly from FY05, decreased in FY07, and increased again in FY08. The number of families that received reimbursement in FY06 also increased slightly from FY05, decreased in FY07, and increased in FY08. From July 1, 2005 through June 30, 2008, the Fund reimbursed 456 families more than \$4.3M.

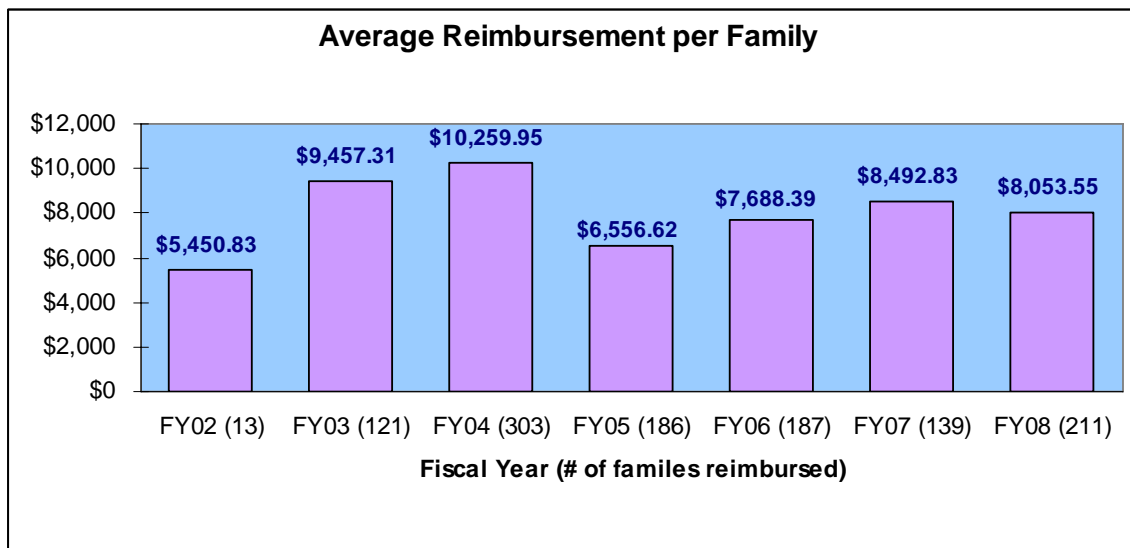
TABLE 5: Reimbursements to Families

	FY06	FY07	FY08	FY01-08
Total	\$ 1,437,729	\$ 1,180,503	\$ 1,699,298	\$ 9,924,085
Minimum	6	36	80	180
Maximum	43,975	25,850	36,384	63,115
Average	7,688	8,492	8,053	12,956
Median	7,191	8,000	6,200	9,736
25 th percentile	3,656	4,575	4,000	5,533
75 th percentile	10,100	10,652	10,000	17,902
Total # families	187	139	211	766

FY01-08 figures represent total payments made to families when all years are combined. It represents an unduplicated number of families, taking into consideration that some families receive payments over multiple years.



See footnote below regarding FY04 reimbursements.⁹



Since the Fund was new in 2001 and only two families were served, the average reimbursement for that year is not reported.

⁹ As explained in the FY05 Annual Report, there were multiple reasons for the dramatic increase in FY04 and subsequent decline in FY05 of reimbursements. They included uncertainty about funding; the cap on use of administrative expenses, which led to a lack of staff resources and resulted in a backlog of applications from families that remained unprocessed until mid-FY05; and further refinement by the Commission of its policy regarding requiring an identifiable twelve-month period of expenses that the Fund can use to reimburse expenses, and limiting reimbursements to expenses incurred during the previous twenty-four months. This more accurately reflected the burden families incurred during a given year and in some cases reduced the reimbursement level.

IV. REVENUE AND EXPENDITURES

The CICRF is funded by quarterly transfers made from the Medical Security Trust, if funds are available after other obligations of the Trust are met¹⁰. During the Fund's initial years of service, there were significant remaining funds at the close of the fiscal year, as the Fund was still fairly unknown and underutilized. As knowledge and utilization of the Fund has increased, the expenditures have increased to match the need. Most notable, in FY08 payment to families increased by 44% compared with FY07. This corresponds to similar increases in the number of applications submitted and numbers of families served.

During FY 2003 and FY 2004 the Fund did not receive the full amount of anticipated transfers from the Medical Security Trust. In fact, during FY 2004 no transfers were made (additional deposits were the result of interest payments). Although this shortfall was offset by the surplus from the Fund's first three years, it potentially poses a significant problem for the future if requisite funding is not received.

Please see the table below for a complete breakdown of annual revenue and expenditures. As illustrated in the table, the level of reserve has grown in each of the last four years, as transfers have exceeded expenditures. However, as awareness of the Fund grows, expenditures are expected to continue to increase.

	Balance from Prior Fiscal Year	Deposits (includes interest)	Expenditures (includes administrative costs)	Balance Forwarded to next Fiscal Year
FY01	--	\$ 2,762,950	\$ 63,062	\$ 2,699,888
FY02	\$ 2,699,888	2,519,271	120,149	5,099,010
FY03	5,099,010	720,771	1,208,507	4,611,274
FY04	4,611,274	47,260	3,171,764	1,486,769
FY05	1,486,769	2,606,336	1,242,563	2,850,541
FY06	2,850,541	2,799,303	1,489,261	4,160,584
FY07	4,160,584	2,845,088	1,292,183	5,713,488
FY08	5,713,488	2,841,943	1,819,146	6,736,284
FY09 <i>projected</i>	6,736,284	2,733,227	2,507,016	6,962,495
FY10 <i>projected</i>	6,962,495	2,600,845	3,254,181	6,309,159
FY11 <i>projected</i>	6,309,159	2,600,845	3,278,353	5,631,650

¹⁰ Chapter 111K, Section 9 of the Massachusetts General Laws provides that funding is to come through an employer's contribution to the office of employment and training, as \$1 annually for each employee "whose wages determine such employer's total unemployment health insurance contribution" under Chapter 151A section 14G of the General Laws.

While this report covers FY06-08, it is important to note Fund projections for FY09-11. As illustrated in the table, expenditures are expected to match or exceed revenue in FY10-11. This anticipated reduction in revenue and increase in expenditures is due to several factors, including an expected decrease in transfers (as unemployment increases, employers' contributions toward the Fund will decrease since they are based on the number of employees); low interest rates; and the current economic downturn, resulting in more families of children with catastrophic illnesses seeking assistance from the Fund.¹¹

V. CONCLUSION

The Catastrophic Illness in Children Relief Fund provides significant support to many families of children with a variety of different of health conditions and special health care needs throughout Massachusetts. The Fund allows children with significant health problems to remain with their families and as a part of their communities. In addition, the illnesses or injuries of the children that the Fund assists demand a wide range of medical services.

Given the number of children with special health care needs in the state, however, it is certain that the Fund could assist many more families by engaging in increased outreach, but its ability to increase marketing efforts and process more applications is constrained by limited staffing levels. Families served by the Fund generally appear satisfied with the assistance they receive, and the numbers of applications continue to increase, but it is likely that the population reached by the Fund is just a small subset of those Massachusetts families who are experiencing tremendous financial hardship due to their child's medical condition.

The diverse needs the Fund encounters attest to the value of this unique safety net. Ultimately, the Fund serves to improve the quality of life for many children and their families.

"I cannot thank you enough for helping me through the hardest battle of my life."

-Recipient Family

¹¹ Projections based on the following assumptions: 4th Quarter FY09 transfer same as the first three quarters; FY10 and FY11 transfers of \$2,486,145, which was the amount in FY05, the lowest of all years with the exception of the years in which not all transfers were received; FY10 and FY11 interest same as FY09 (approximately \$114,483); 20% increase in payments to families in FY10, based on the FY08 to FY09 increase of 35%, and the fact that more staff in FY10 will allow for processing of backlog of applications; payments to families same in FY10 and FY11; current staffing levels.

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