

The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
250 Washington Street, Boston, MA 02108-4619

MAURA T. HEALEY
Governor

KIMBERLEY DRISCOLL
Lieutenant Governor

KATHLEEN E. WALSH
Secretary

ROBERT GOLDSTEIN, MD, PhD
Commissioner

Tel: 617-624-6000
www.mass.gov/dph

March 11, 2025

Timothy Carroll
House Clerk
State House Room 145
Boston, MA 02133

Michael D. Hurley
Senate Clerk
State House Room 335
Boston, MA 02133

Dear Mr. Clerk,

Pursuant to *M.G.L. Chapter 111K, Section 11*, please find enclosed a report from the Department of Public Health entitled, *The Catastrophic Illness in Children Relief Fund Annual Report Fiscal Year 2023*.

Sincerely,

A handwritten signature in black ink, appearing to read "Robbie Goldstein".

Robbie Goldstein, MD, PhD
Commissioner
Department of Public Health

Legislative Mandate

M.G.L. Chapter 111K: Section 11. Annual report

Section 11. The commission shall report annually to the governor and the senate and house committees on ways and means. 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 receive financial assistance under the program. The commission shall also make recommendations for changes in the law and regulations governing the fund.

LETTER FROM THE COMMISSION CO-CHAIRS

On behalf of the Catastrophic Illness in Children Relief Fund (CICRF) Commission, we are pleased to provide this annual report for Fiscal Year 2023 pursuant to M.G.L. Chapter 111K, Section 11.

CICRF provided nearly \$2.35 million in FY2023 in financial assistance directly to families or to vendors on behalf of families for medical related expenses for children and youth with special health needs.

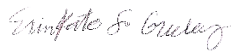
During FY2023, CICRF worked closely with a developer to customize and test a new Customer Relationship Management (CRM) system to replace the outdated Access database. CICRF also developed a new electronic application to reduce paper-based files and make it more convenient for families to apply to the Fund. Families provided input on the new online application and were compensated for their time and feedback. The CRM system and new online application will be implemented in FY2024 along with a reengineered workflow to streamline the application review process, reduce the wait time for families to receive confirmation of their eligibility for financial assistance, and enhance monitoring controls and performance standards.

The Commission welcomes your input as we seek to improve our ability to serve children and families.

Sincerely,



John S. Maypole, MD
Co-Chair, CICRF Commission



ErinKate Greeley
Co-Chair, CICRF Commission

EXECUTIVE SUMMARY

Purpose of the Fund

The Catastrophic Illness in Children Relief Fund (CICRF) was established by legislation for FY2001 to provide assistance to families for catastrophic medical and related expenses that are not covered by insurance, public benefits, or other financial sources. Massachusetts families with children 21 years of age and younger 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. The CICRF continues to support some of the most vulnerable children in Massachusetts, improving financial stability for eligible families. Between FY2001 and FY2023, the CICRF provided over \$39.2 million in reimbursements to the families of 2,724 children.

Fiscal Year 2023 Data Highlights

- During FY2023, 142 families received nearly \$2.35 million in reimbursements. The median reimbursement was \$7,613 per family.
- The children assisted by the CICRF have a variety of diagnoses, typically coming from families with lower incomes, and have health insurance coverage. Most notably, during FY2023, approximately 66% of the families who received assistance had annual incomes of less than 200% of the federal poverty level and approximately 37% of the children who were helped during this period were under age five at the time the application was submitted.
- The CICRF supports a wide variety of non-covered services, including medical equipment, medical services, hospital and physician services, medications, family support, and home and vehicle modifications that enable children to live more comfortably at home and in their communities.
- CICRF also provides referrals and technical assistance related to accessing other financial resources, such as information on low interest loans for accessible vehicles through Easter Seals.
- Five out of six CICRF program coordinators speak languages other than English (Spanish and Haitian-Creole), improving program capacity to explain documentation needs and complex Fund policies directly to families.
- The CICRF ended FY2023 with a balance of \$6,251,374.11.

TABLE OF CONTENTS

| | |
|--|---------------|
| Legislative Mandate..... | i |
| Letter from the Commission Co-Chairs..... | ii |
| Executive Summary..... | iii |
| Table of Contents | iv |
| I. Introduction | 1 |
| II. Catastrophic Illness in Children Relief Fund Program | 2 |
| Eligibility | 2 |
| Eligible Services | 2 |
| Commission Responsibilities..... | 3 |
| III. Data..... | 3 |
| Fund Accomplishments and Highlights..... | 3 |
| Applications Received in Fiscal Year 2023 | 4 |
| Families Receiving Financial Assistance in Fiscal Year 2023 | 5 |
| Reimbursements to Families..... | 5 |
| Diagnoses..... | 7 |
| Funded Services | 8 |
| Income Level | 10 |
| Insurance Status | 11 |
| Geography..... | 12 |
| Age..... | 13 |
| Race..... | 14 |
| IV. Revenue and Expenditures..... | 15 |
| V. Conclusion..... | 17 |
| VI. Commission Member List | 18 |

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 significant medical and related expenses. It provides last resort financial assistance for families in Massachusetts who are struggling to pay for medical or related expenses not covered by a private insurer, federal or state health care assistance, or any other financial source.

The CICRF was established within the Department of Public Health (DPH), in accordance with M.G.L. Chapter 29, Section 2ZZ, and is administered by the CICRF Commission, which was established and is governed by M.G.L. Chapter 111K. 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 FY2007 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 (four state agency ex-officio members and seven public members) and is staffed by DPH. The Fund is financed by quarterly transfers from the Commonwealth Care Trust if sufficient funds are available.

The cost of caring for a chronically ill child can be overwhelming, even to a family with health insurance. High insurance premiums, deductibles, co-insurance and co-payments, combined with medical and related expenses incurred because of coverage limitations and exclusions, can result in a serious drain of a family’s financial resources. The bills incurred can send the family into extreme debt and cause severe emotional stress. According to the Kaiser Family Foundation, medical debt – and a host of related problems – can result when people cannot afford to pay their medical bills. While the chances of falling into medical debt are greater for people who are uninsured, most people who have trouble paying medical bills have health insurance. Medical debt can arise when people must pay out-of-pocket for care not covered by health insurance or to which cost-sharing (such as deductibles and co-insurance) applies. Medical debt also might result from health insurance premiums that individuals find difficult to afford. The consequences of medical debt can be severe. People with unaffordable medical bills report higher rates of other problems – including difficulty affording housing and other necessities, credit card debt, bankruptcy, and barriers accessing health care.¹ In the 2022 National Survey of Children’s Health (NSCH), 10.9% of families with children with special health needs in Massachusetts reported having problems paying for their child’s medical or health care bills within the past 12 months.²

¹ K. Pollitz, C. Cox et alia, Medical Debt Among People with Health Insurance, January 2014. <https://kaiserfamilyfoundation.files.wordpress.com/2014/01/8537-medical-debt-among-people-with-health-insurance.pdf>

² Child and Adolescent Health Measurement Initiative. 2022 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website, <http://www.childhealthdata.org/>

The impact of a child's illness can have severe ripple effects. The time and energy necessary to care for a sick child often places further debilitating strain on a family and often results in loss of employment for one or both parents. In the NSCH, 19.6% of Massachusetts families with children with special health needs reported having to cut back or stop working due to their child's condition.² In such situations, the family loses not only income, but frequently also loses continuity of health benefits, since access to health insurance is often through one's employer. The family must then identify other insurance coverage, which may involve accessing a different provider network for their child and paying higher health insurance premiums, further adding to family stress. There are also many expenses resulting from a child's medical condition that are not covered by insurance. In the NSCH, 21.2% of Massachusetts families of children with special health needs reported having to pay between \$1,000 and \$5,000 in out-of-pocket medical, health, dental and vision care during the past 12 months, and only 58.8% reported having continuous and adequate private and/or public insurance to pay for the services they need.² The CICRF thus provides valuable, stabilizing financial and emotional relief for families facing incredible life challenges.

II. CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND PROGRAM

Eligibility

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

- Is 21 years of age or younger
- 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 more than \$100,000, after all other avenues of reimbursement have been exhausted)

Eligible Services

Consistent with the Community First Olmstead Plan and the Administration's support of community-based rather than institutional care, the CICRF supports children to remain at home in their communities to the maximum extent feasible. It therefore considers reimbursement to families for a broad range of 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:

- Medically related home and vehicle modifications
- Travel and incidental expenses associated with a child's admissions and outpatient care
- Insurance co-payments, coinsurance and deductibles
- Mobility equipment and other medical supplies
- Medications

- CommonHealth and MassHealth premiums
- Funeral expenses

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 who apply to the Fund seek assistance with multiple expenses. As a payor of last resort, the CICRF ensures that 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 11 members (see current Commission Member list), 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 three providers of health care services to children in Massachusetts, and a parent of a child with special health needs). 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 Commission's goal is to act in the best interest of the child while ensuring the Fund remains the payor of last resort.

The Department of Public Health 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. DPH staff devotes 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 assists the applicant in applying for alternate benefits and resources.

III. DATA

Fund Accomplishments and Highlights

From its inception through FY2023, the CICRF provided funds to 2,724 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.

CICRF has proven to be an invaluable resource for families struggling with the need to preserve family life in the face of substantial 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 in FY2023 ranged from a low of \$698 to a high of \$54,190.³ The median amount was \$7,613; the mean was \$16,547 (later sections in this report provide more information on services supported and reimbursements). Some families have been eligible to receive CICRF assistance over multiple fiscal years.

Applications Received in Fiscal Year 2023

From FY2001 through FY2023, 6,188 applications were submitted to the CICRF. Table 1 shows the number of applications submitted each year for the last five years. The number of first-time applicants was 62% of applications received in FY2023, which indicates that new families are aware of the help the Fund can provide. The COVID-19 pandemic lockdown starting in March 2020 with continued system impact through 2023 resulted in fewer new children being referred to CICRF.

TABLE 1: Applications Submitted

| | FY 2019 | FY 2020 | FY 2021 | FY 2022 | FY 2023 | FY 2001- 2023 |
|---|----------------|----------------|----------------|----------------|----------------|----------------------|
| First-time applicants | 232 | 243 | 149 | 173 | 156 | 4,523 |
| Re-applicants (first application received in a previous year or earlier that year) | 89 | 109 | 81 | 93 | 95 | 1,665 |
| TOTAL applications | 321 | 352 | 230 | 266 | 251 | 6,188 |
| % of applications received that were from families applying for the first time | 72% | 69% | 65% | 65% | 62% | 73% |

CICRF staff has determined the eligibility status for 96% of the 251 applications submitted to the Fund in FY2023: 50% (126) were eligible and resulted in payments to the family; another 21% (52) were determined ineligible because they did not meet the financial, age or residency criteria; and 25% (62) of applications initiated were not completed by the family or other resources were found. The remaining 4% (11) of the 251 applications received in FY2023 are in the process of eligibility review and determination by CICRF staff.

³ For some families, most of the reimbursements were received in a prior fiscal year. For others, payment in FY2023 could include expenses incurred over several years.

Families Receiving Financial Assistance in Fiscal Year 2023⁴

Unless otherwise indicated, the data below are based on the 142 families who received financial assistance from the Fund (“families served”) in FY2023.

Applications may be received in one fiscal year and associated reimbursements may not occur until the following fiscal year due to the timing of receipt of applications and the documentation required for eligibility determination. Also, one application may result in multiple payments over time, sometimes in multiple fiscal years.

Reimbursements to Families

Total reimbursements to families in FY2023, and in all years since the creation of the Fund, are shown in Tables 2 and 3. From July 1, 2022 to June 30, 2023, the Fund reimbursed nearly \$2.35 million to 142 families.

TABLE 2: Reimbursements to Families

| | FY 2023 | FY 2001 – 2023* |
|-----------------------------|----------------|------------------------|
| Minimum | \$ 698 | \$ 30 |
| Maximum | \$ 54,190 | \$ 110,145 |
| Average | \$ 16,547 | \$ 14,235 |
| Median | \$ 7,613 | \$ 7,963 |
| 25 th percentile | \$ 4,889 | \$ 4,724 |
| 75 th percentile | \$ 31,930 | \$ 19,176 |
| Total # families | 142 | 2,724 |

* FY2001-2023 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.

⁴ For all FY2001-FY2023 charts, the total number of unique children is 2,724; for FY2023 charts, the total number of children is 142. All data are derived from the Massachusetts Department of Public Health Catastrophic Illness in Children Relief Fund database, 2023.

TABLE 3: Reimbursements to Families since the Inception of the Fund

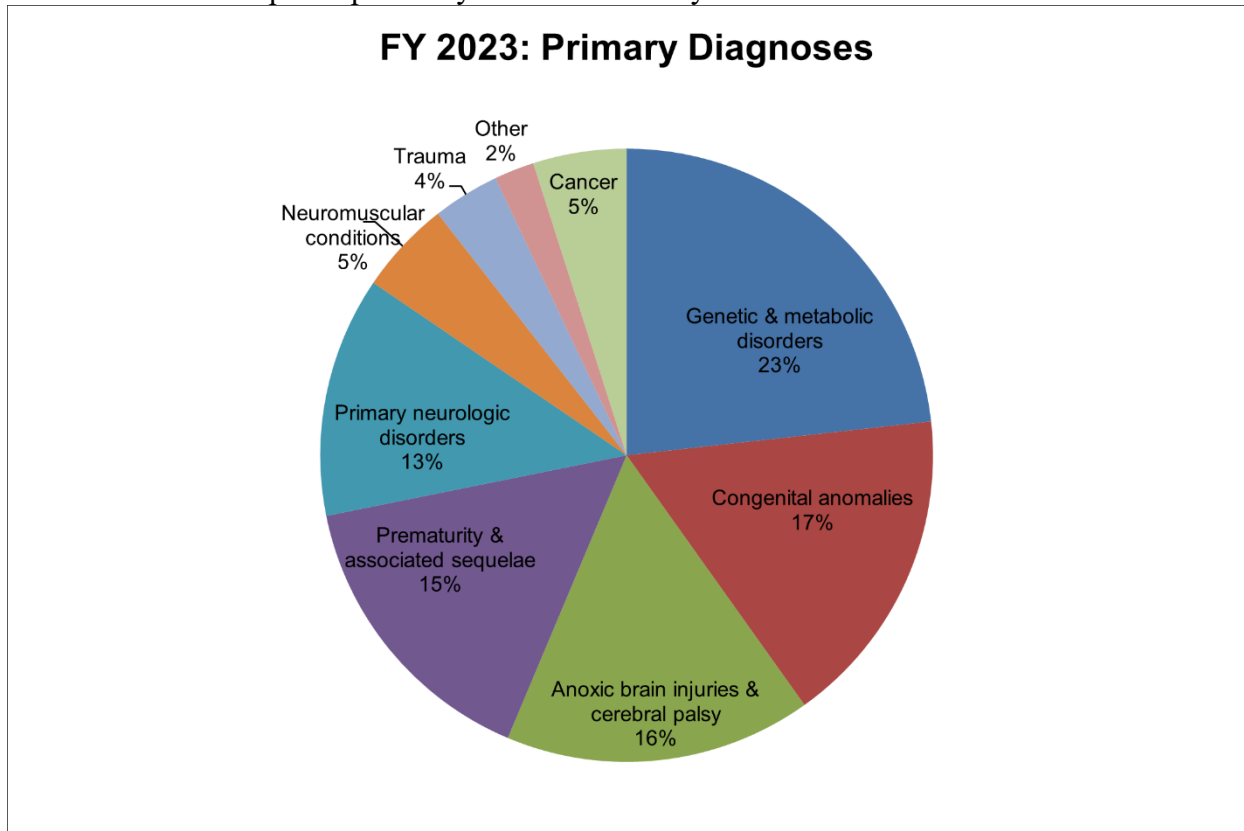
| | Total Amount Reimbursed (\$) | Number of Families Receiving Assistance | Average Amount per Family (\$) |
|----------------------------|-------------------------------------|--|---------------------------------------|
| FY 2001 | 63,062 | 2 | 31,531 |
| FY 2002 | 70,861 | 13 | 5,451 |
| FY 2003 | 1,144,335 | 121 | 9,457 |
| FY 2004 | 3,108,764 | 303 | 10,260 |
| FY 2005 | 1,219,532 | 186 | 6,557 |
| FY 2006 | 1,437,730 | 187 | 7,688 |
| FY 2007 | 1,180,503 | 139 | 8,493 |
| FY 2008 | 1,699,299 | 211 | 8,054 |
| FY 2009 | 2,277,800 | 261 | 8,727 |
| FY 2010 | 2,561,725 | 286 | 8,957 |
| FY 2011⁵ | 1,946,417 | 248 | 7,848 |
| FY 2012 | 1,467,282 | 171 | 8,581 |
| FY 2013 | 1,993,984 | 197 | 10,122 |
| FY 2014 | 1,634,726 | 163 | 10,029 |
| FY 2015 | 1,780,983 | 182 | 9,786 |
| FY 2016 | 2,056,724 | 210 | 9,794 |
| FY 2017 | 1,663,413 | 171 | 9,728 |
| FY 2018 | 1,620,321 | 190 | 8,528 |
| FY 2019 | 1,928,442 | 191 | 10,097 |
| FY 2020 | 2,090,867 | 169 | 12,372 |
| FY 2021 | 1,927,509 | 166 | 11,612 |
| FY 2022 | 1,978,614 | 160 | 12,366 |
| FY 2023 | 2,349,717 | 142 | 16,547 |

⁵ As explained in the FY2010 Annual Report, in mid-FY2010, faced with decreased revenues and increased applications, the Commission made significant changes to reimbursement policy, with the intended effect of reducing per-family reimbursements. The Commission's aim was to assist as many families as possible while ensuring funds remained to assist families in FY2011 and beyond. This is partly responsible for the decrease in total reimbursements after FY2010.

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 associated conditions that dramatically impact the lives of the children including seizure disorders, vision and hearing loss, incontinence, respiratory conditions, and inability to eat safely by mouth. Often children with these challenges are entirely dependent on others for aspects of daily living, such as getting dressed, toileting, or 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 chart below summarizes the types of conditions of the children assisted by the CICRF in FY2023. The six categories of conditions comprising 80% of the children supported by the Fund were: genetic and metabolic disorders, anoxic brain injuries and cerebral palsy, prematurity and associated conditions, congenital anomalies, primary neurologic disorders and cancer. Numerous children assisted by the Fund had multiple diagnoses that would fit into more than one diagnostic category. Many of the conditions are chronic and require significant, ongoing medical care and/or pharmaceutical regimens. Other conditions severely impact mobility, resulting in families needing to make their living space and modes of transportation accessible to the child to allow the child to live and participate fully in the community.



Funded Services

The Fund reimburses families for a diverse set of medically related services and expenses. Reimbursable expenses are defined in the Fund's policies set by the Commission. The Commission – with Fund staff support – reviews policies regularly to respond to feedback from families and referral sources as well as changes in medical practice, technology, insurance coverage and available monies in the Fund. After analyzing the financial impact of any policy change on the Fund, the Commission must vote to approve the policy change. In general, if a family meets the eligibility criteria for the Fund, then CICRF reimburses the family according to the Fund's sliding fee scale.⁶

Examples of eligible expenses include medical supplies and equipment, such as stair lifts; 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 payment for medical and related services, such as co-payments and deductibles.

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 to care for their child at home (such as an accessible bathroom or a wheelchair accessible home entrance/exit). The Fund also assists families who need an accessible vehicle to transport their child to medical visits and elsewhere within the community.⁷ The largest percent of payments to families in FY2023 was for expenses related to vehicle purchases and/or modifications, accounting for over half (68.2%) of all reimbursements to families.

The next highest (17.2%) was for Family Support, a per diem stipend toward expenses parents incur while being with and caring for a sick child in the hospital or expenses incurred by driving to outpatient appointments, such as in-state transportation costs, parking, meals, etc. Many children have multiple and/or lengthy hospitalizations – sometimes for months at a time – and the presence of parents at the hospital and parental involvement in the child's care team are critical components to the child's care, making this support essential.

⁶ There are additional limitations to the amount of reimbursement for certain types of expenses, including home and vehicle modifications, vehicle purchases, funeral expenses, whole house generators and short-term placements.

⁷Vehicle purchases and modifications are reimbursed according to a sliding scale based on income; families have a lifetime limit on the total amount that the Fund will reimburse for these types of expenditures which is also determined by a sliding scale.

TABLE 4: FY 2023 Expenditures by Expense Category

| Expense Category | FY 2023 Amount | Percent of total expenditures* |
|---|------------------------|---------------------------------------|
| Vehicle purchase and/or modification | \$ 1,603,668.60 | 68.2% |
| Family support | \$ 402,995.00 | 17.2% |
| Home modification | \$ 111,620.03 | 4.8% |
| Equipment and medical supplies | \$ 99,162.06 | 4.2% |
| Funeral expenses | \$ 73,258.75 | 3.1% |
| Medical services (physician, hospital, ancillary, home health care) | \$ 39,405.01 | 1.7% |
| Medication/nutritional supplements | \$ 14,834.59 | 0.6% |
| Family travel & lodging (primarily related to out-of-state treatment) | \$ 4,773.00 | 0.2% |
| Total Expenditures | \$ 2,349,717.04 | 100.0% |

As children grow, their needs change, and families may reapply to the Fund for additional assistance. For example, as children get older, they outgrow certain equipment, such as leg braces and wheelchairs, which require replacement or modification 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.

Income Level

The CICRF provides financial assistance to families at all income levels, but 77% of the families helped by the CICRF in FY2023 had incomes under 300% of the federal poverty level (FPL); this is a measure of family income that is calculated each year by the U.S. Department of Health and Human Services (USDHHS). It is used to determine financial eligibility for a variety of programs, for example, MassHealth eligibility for children extends to 300% of FPL. These guidelines are a simplified version of the “poverty thresholds” developed by the U.S. Census Bureau.⁸ In Calendar Year 2023, 300% of FPL was \$90,000 for a family of four.

Often a family with a catastrophically ill child had large, immediate expenses which, in conjunction with their low-income level, made traditional loans unavailable or unaffordable. For some families, the Fund represented a major and sometimes sole source of hope and support.

TABLE 5: Family Income, by Percent of Federal Poverty Level (FPL)

| % of FPL | FY 2023 | |
|-----------------------|-----------------|-----------------------------|
| | Number | % of Total Families Served* |
| ≤ 200% | 94 | 66.2% |
| 201-300% | 15 | 10.6% |
| 301-400% | 12 | 8.5% |
| 401-600% | 15 | 10.6% |
| 601-800% | 3 | 2.1% |
| >800% | 3 | 2.1% |
| Total | 142 | 100% |
| Average income | \$53,930 | |
| Median income | \$35,817 | |

*Percents may not total 100% due to rounding.

⁸ <http://aspe.hhs.gov/poverty/faq.shtml>.

Insurance Status

All children assisted by the CICRF in FY2023 had health insurance.⁹ Nevertheless, these families still had catastrophic medical or related expenses. Often this is because the insurance did not cover certain services or expenses, such as home and vehicle modifications. Families with private insurance can have significant co-payments, co-insurance, or deductibles associated with care. Medically complex children and youth seeing multiple ancillary providers (e.g., physical therapy, occupational therapy, speech therapy) can reach benefit limits under private insurance depending upon the individual plan. Other times, families with private health insurance do not qualify for secondary MassHealth insurance right away. Since Fund staff consider expenses incurred up to 24 months prior to the date of the application, a family might not have secondary insurance when an expense was incurred but does have secondary insurance at the time of their CICRF application, when insurance type is entered into the Fund database. Fund staff make every effort to ensure insurance is used first and the Fund is the payor of last resort.

The table below shows the insurance coverage of the families reimbursed by CICRF in FY2023. Most families with private insurance had secondary state Medicaid (MassHealth) coverage. Almost all families had some form of MassHealth as a primary or secondary insurer.

As noted in the chart, a small percentage of children had MassHealth Limited, which is emergency medical coverage for non-citizens who meet MassHealth eligibility except for their immigration status. While most of those children were also covered by the Children's Medical Security Plan (CMSP) for basic health coverage, CMSP and MassHealth Limited does not support all the service, medication and equipment needs of children with chronic or complex medical conditions.

TABLE 6: Primary Insurance

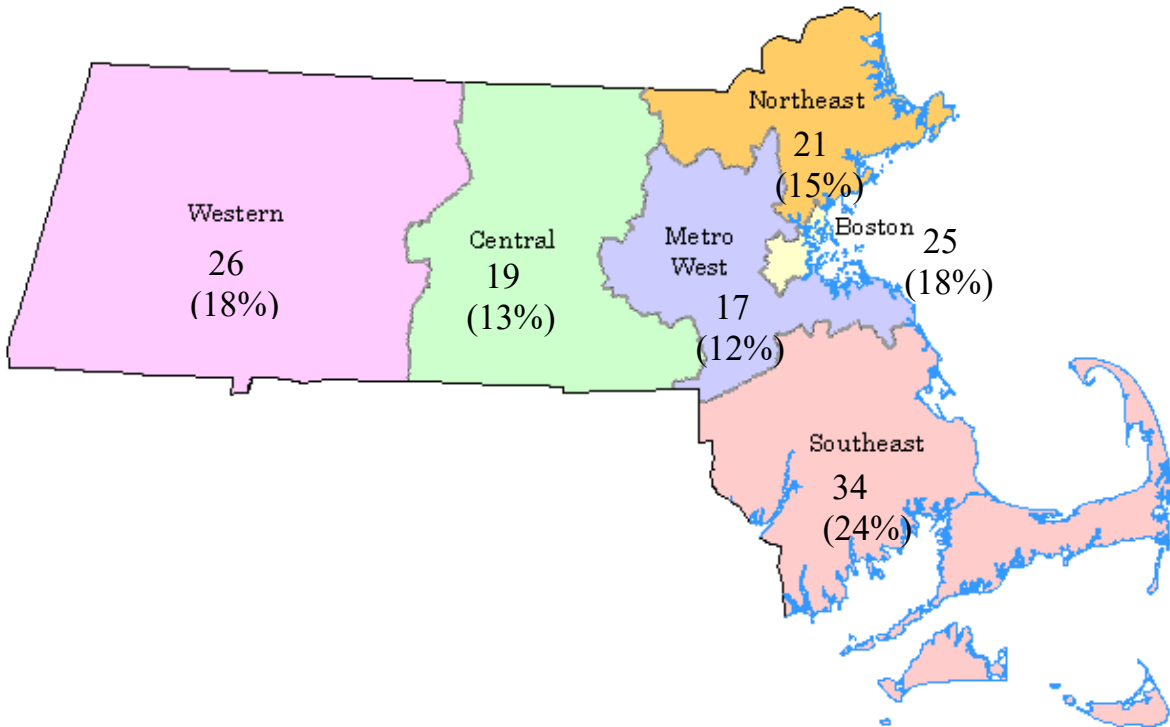
| | FY 2023 | |
|--|--------------|----------|
| Primary Insurance | Number | Percent* |
| <i>MassHealth Standard</i> | 92 | 64.8% |
| <i>Private/Other</i> | 36 | 25.4% |
| <i>MassHealth Limited</i> | 14 | 9.8% |
| Total | 142 | 100.0% |
| Number of privately insured with secondary MassHealth ¹⁰ coverage | 34 | |
| % with MassHealth as primary or secondary insurer | 98.6% | |

⁹ If a family applies to the CICRF and staff learns 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.

¹⁰ Includes MassHealth Standard, CommonHealth and Kaileigh Mulligan.

Geography

The CICRF serves children and families from across all regions of Massachusetts. Fund staff conducts outreach activities in collaboration with the DPH Division for Children & Youth with Special Health Needs. Most 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 map below shows the number of families served by region for FY2023 for a total of 142 families.



Age

The table below shows the breakdown of age at time of application for the children reimbursed in FY2023. The average age was 8.7 years in FY2023. Approximately 37.3% of the children served in FY2023 were under age five. 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 time.

TABLE 7: Age at Time of Application

| | FY 2023 | |
|----------------------|---------|---------|
| | Number | Percent |
| <i>Under age 1</i> | 21 | 14.8% |
| <i>1 – 4 years</i> | 32 | 22.5% |
| <i>5 – 9 years</i> | 28 | 19.7% |
| <i>10 – 14 years</i> | 28 | 19.7% |
| <i>15 – 18 years</i> | 22 | 15.5% |
| <i>19 – 21 years</i> | 11 | 7.8% |
| Total | 142 | 100.0% |

Race

The table below shows the breakdown of families served by child's race, as reported on the application.

TABLE 8: Families Served, by Race ^a

| | FY 2023 | |
|--|------------|-------------|
| | Number | Percent* |
| <i>White, non-Hispanic</i> | 51 | 36% |
| <i>Hispanic/Latino/Black, Hispanic/Latino/White, Hispanic/Latino/Other</i> | 49 | 35% |
| <i>Black, non-Hispanic</i> | 23 | 16% |
| <i>Other</i> | 10 | 6% |
| <i>Asian</i> | 4 | 3% |
| <i>Unknown</i> | 3 | 2% |
| <i>Multi-racial ^b</i> | 2 | 1% |
| Total | 142 | 100% |

*Percents may not total 100% due to rounding.

^a Based on what is written on the application, either by the family or a referral source who may have helped the family with the application. Response options provided on the current application are: American Indian or Alaska Native; Asian; Black; Hispanic/Latino/Black; Hispanic/Latino/White; Hispanic/Latino/Other; Native Hawaiian or Other Pacific Islander; White; and Other.

^b Multi-racial is not a response option on the application. The child was considered multi-racial if more than one of the other response options were checked on the application.

IV. REVENUE AND EXPENDITURES

CICRF is funded by quarterly transfers made from employers' contributions to the Commonwealth Care Trust if funds are available after other obligations have been met.^{11,12} In approving the annual Fund budget each year, the Commission has agreed that there should always be at least one year's reserve on hand since the total amount of transfers into the Trust each year is unknown and not guaranteed.

In FY2023, four transfers were made into the CICRF Trust. Total deposits (transfers plus interest) were almost \$3.1 million, while total expenditures for payments to families, staffing and other expenses were slightly under \$3.5 million. FY2023 ended with a healthy balance of \$5.8 million.

Table 9 on the next page lists a breakdown of annual revenue and expenditures from the CICRF Trust.

¹¹ Prior to January 1, 2014: 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.

¹² As of January 1, 2014: Chapter 111K, Section 9 of the Massachusetts General Laws provides that funding is to come through an employer's medical assistance contribution under section 189 of chapter 149, "\$1 annually for each employee whose wages determine such employer's total employer medical assistance contribution."

TABLE 9: Annual Revenue and Expenditures from CICRF Trust

| | Balance from Prior Fiscal Year (\$) | Deposits (includes interest) (\$) | Expenditures (includes administrative costs) (\$) | Balance Forward to Next Fiscal Year (\$) |
|--------------------------------|--|--|--|---|
| FY 2001 | -- | 2,762,950 | 63,062 | 2,699,888 |
| FY 2002 | 2,699,888 | 2,519,271 | 120,149 | 5,099,010 |
| FY 2003¹³ | 5,099,010 | 720,771 | 1,208,507 | 4,611,274 |
| FY 2004¹³ | 4,611,274 | 47,260 | 3,171,764 | 1,486,769 |
| FY 2005 | 1,486,769 | 2,606,336 | 1,242,563 | 2,850,541 |
| FY 2006 | 2,850,541 | 2,799,303 | 1,489,261 | 4,160,584 |
| FY 2007 | 4,160,584 | 2,845,088 | 1,292,183 | 5,713,488 |
| FY 2008 | 5,713,488 | 2,841,943 | 1,819,146 | 6,736,284 |
| FY 2009¹³ | 6,736,284 | 2,070,541 | 2,487,524 | 6,319,302 |
| FY 2010¹³ | 6,319,302 | 23,293 | 3,051,570 | 3,291,025 |
| FY 2011¹³ | 3,291,025 | 16,066 | 2,425,395 | 881,695 |
| FY 2012^{13,14} | 881,695 | 2,098 | 639,952 | 243,842 |
| FY 2013^{13,14} | 243,842 | 572 | 228,907 | 15,507 |
| FY 2014^{13,14} | 15,507 | 3,323,428 | 615,421 | 2,723,515 |
| FY 2015 | 2,723,515 | 2,903,247 | 2,233,697 | 3,393,064 |
| FY 2016 | 3,393,064 | 3,033,103 | 2,612,305 | 3,813,862 |
| FY 2017 | 3,813,862 | 3,046,230 | 2,286,280 | 4,573,812 |
| FY 2018 | 4,573,812 | 3,075,178 | 2,328,516 | 5,320,473 |
| FY 2019 | 5,320,473 | 3,135,460 | 2,774,665 | 5,681,268 |
| FY 2020 | 5,681,268 | 3,177,630 | 3,001,912 | 5,856,986 |
| FY 2021 | 5,856,986 | 2,892,775 | 2,728,183 | 6,021,578 |
| FY 2022 | 6,021,578 | 2,848,854 | 2,728,183 | 6,251,374 |
| FY 2023 | 6,251,374 | 3,078,661 | 3,477,498 | 5,852,537 |

¹³ During FY2003, FY2004, and from FY2009-FY2013 the Fund did not receive the full number of anticipated transfers from the Medical Security Trust. In FY2004 and from FY2010-FY2013, no transfers were made; deposits reflect interest payments only. Transfers resumed in FY2014; five transfers were received in FY2014 because the 4th quarter FY2013 transfer was made in early FY2014.

¹⁴ As explained on the previous page, state appropriated funds were used to supplement CICRF Trust funds in FY2012-FY2014; only those expenditures from the CICRF Trust are represented here.

V. CONCLUSION

The Catastrophic Illness in Children Relief Fund provides vital support to families of children with varied and significant 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 the Fund assists demand a wide range of medical services.

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.

The Commission is proud of the assistance the Fund has provided to families over the past 23 years.

VI. COMMISSION MEMBER LIST

As of February 2024

Public Members

John S. Maypole, MD
Co-chair

ErinKate Greeley
Co-chair

Elizabeth Childs, MD, MPA

Laura-Jean Hickey, MEd
AFL-CIO Representative

Donna Nimec, MD

Jorge Pagan-Ramos

Victoria Pulos, JD

Ex Officio Members

Deborah B. Goldberg
*Treasurer and Receiver General
Office of the State Treasurer*

Kathleen E. Walsh
*Secretary
Executive Office of Health and Human Services*

Robert Goldstein, MD, PhD
*Commissioner
Department of Public Health*

Gary D. Anderson
*Commissioner
Division of Insurance*

Commissioner Emerita

Marcia Huttner, MLS

Designee

Emily Kowtoniuk

Carolyn Kain

Scott Geer

Rita Gallo