

The Catastrophic Illness in Children Relief Fund

*When other resources end, we begin.*

## The Catastrophic Illness in Children Relief Fund

### Annual Report: Fiscal Year 2018



*“Over the years, the Fund has supported us through several financial obligations that parents never expect or plan on when a child is born ... The Fund has lessened our stress around providing our son the care he needs at home with us. With our handicapped van, ramp, and more appropriate bathroom, we can keep him safe and maintain our ability to be his caregivers.”*

*- Recipient Family*

**Submitted by:  
The Catastrophic Illness in Children Relief Fund Commission**

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## LETTER FROM THE COMMISSION CO-CHAIRS

January 2019

On behalf of the Catastrophic Illness in Children Relief Fund Commission, we are pleased to provide this annual report for Fiscal Year 2018.

The Catastrophic Illness in Children Relief Fund (CICRF) continues to support some of the most vulnerable children in Massachusetts, improving financial stability for eligible families. In FY2018, the Fund completed its 18<sup>th</sup> 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 2,204 children (through FY2018) from all across the state.

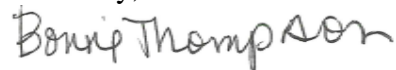
Despite almost universal health insurance coverage, families of children with special health needs in the Commonwealth continue to experience financial hardship as a result of their children's conditions. In many instances, the Fund fills the gaps left by traditional insurance coverage, helping families 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.

Over the past several years, CICRF implemented a multi-pronged approach to streamline the review and eligibility determination process for applications by needy families struggling to care for children with extensive medical needs. A staffing analysis conducted in FY2018 indicated that additional staff was needed and DPH approved two new positions. Two new staff started training in March 2018. Increasing DPH staff and expediting the review process has resulted in a significant reduction of the backlog of applications from a high of 175 at the beginning of FY18 to 114 currently. Further backlog reduction is the program priority for FY2019.

In FY2018, major updates were made to both the English and Spanish versions of the CICRF websites, making it easier for families and referral sources to find information and download forms. Five out of six CICRF program coordinators speak other languages (Spanish, Haitian-Creole and Portuguese), improving program capacity to explain documentation needs and complex Fund policies directly to families. CICRF staff has participated in racial equity trainings spearheaded by the DPH Bureau of Family Health and Nutrition, and continue to incorporate these values and initiatives in all program efforts.

The Commission welcomes your comments, feedback and ideas as we seek to improve our ability to serve children and families.

Sincerely,



Bonnie Thompson, BS, Co-Chairperson  
CICRF Commission



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

## **EXECUTIVE SUMMARY**

### **Purpose of the Fund**

The Catastrophic Illness in Children Relief Fund (CICRF) was established by legislation for FY2001. 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 FY2018, it has provided over \$28.9 million in reimbursements to the families of 2,204 children with special health needs and disabilities 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 Year 2018 Summary**

- During FY2018, 190 families received nearly \$1.62 million in reimbursements. The median reimbursement was \$5,615 per family.
- Knowledge about the Fund continues to grow. In FY2018, 70% of the applications submitted were from first-time applicants.
- The children who have been assisted by the CICRF have a variety of different diagnoses, typically come from families with lower incomes, and have some form of health insurance coverage. Most notably, during FY2018, approximately 80% of the families who received assistance had annual incomes of less than 200% of the federal poverty level (\$50,200 for a family of four in 2018), and approximately 49.4% of the children who were helped during this period were under the age of five at the time the application was submitted.
- The CICRF supports a wide variety of services, if not covered by health insurance, 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 additional 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.
- The CICRF ended FY2018 with a balance of \$5,320,473.37.

***“Thank you CICRF for your assistance. As you know there are many factors that impact caring for a medically complex child. [My daughter] has made amazing gains due to the support you have given us.”***

***- Recipient Family***

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## **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 who 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 FY2001, the Fund has served more than 2,200 families from across Massachusetts, providing basic support to help families care for their children at home.

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 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 the Department of Public Health. The Fund is financed by quarterly transfers from the Commonwealth Care Trust, if sufficient funds are available. (See page 16 for more detailed information about the funding of the CICRF.)

From its inception through FY2018, the CICRF provided funds to 2,204 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, co-insurance 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 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 experience difficulty 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 basic necessities, credit card debt, bankruptcy, and barriers accessing health care.<sup>1</sup> One study by Himmelstein, et al, showed that medical debt is responsible for 62% of all bankruptcies nationally.<sup>2</sup> In the 2016 National Survey of Children’s Health (NSCH), 16.6% 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.<sup>3</sup>

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 result in loss of employment of one or both parents. (In the NSCH, 19.9% of Massachusetts families with children with special health needs reported having to cut back or stop working due to their child’s condition.<sup>3</sup>) 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, 20.4% 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 63% reported having continuous and adequate private and/or public insurance to pay for the services they need.<sup>3</sup>) The CICRF thus provides valuable or stabilizing financial and emotional relief for families facing incredible life challenges.

***“Thank you so much for reimbursing us for our child’s surgery at Boston Children’s Hospital and other expenses. That money meant so much to us. We are now not living paycheck to paycheck and we have caught up on our bills. Thank you so much for caring about our family and making our lives a little easier.***

***-Recipient Family***

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<sup>1</sup> 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>

<sup>2</sup> D.U. Himmelstein, D. Thorne, E. Warren, S. Woolhandler. Medical Bankruptcy in the US: Results of a National Study. American Journal of Medicine. August 2009. Volume 122, Issue 8, Pages 741-746.

<sup>3</sup> Child and Adolescent Health Measurement Initiative. 2016 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website, <http://www.childhealthdata.org/>

## **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 younger<sup>4</sup>
- 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**

Consistent with the Community First Olmstead Plan and the Administration's support of community-based rather than institutional care, the CICRF has a strong desire to help children remain at home in their communities. 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:

- 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, co-insurance 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 who apply to the Fund seek assistance with multiple expenses. As a payor 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.

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<sup>4</sup> 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.

## Commission Responsibilities

The CICRF Commission consists of 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). Current Commission members are listed on page 19, and include 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 (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. 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 the establishment of the CICRF in FY2001 through FY2018, the Fund has provided over \$28.9 million in reimbursements to 2,204 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 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 FY2018 ranged from a low of \$60 to a high of \$35,700<sup>5</sup>. The median amount was \$5,615; the average was \$8,528. (See pages 13-15 for more information on services supported and reimbursements.) Some families have been eligible to receive CICRF assistance over multiple fiscal years.

***“I am grateful in knowing that there is an organization that understands the overwhelming struggles of having a child with medical issues and that has ensured funding is available to assist those in need.”***

***- Recipient Family***

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<sup>5</sup> For some families, a majority of the reimbursements were received in a prior fiscal year. For others, payment in FY2018 could include expenses incurred over several years.



## Applications Received in Fiscal Year 2018

From FY2001 through FY2018, 4,768 applications have been 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 has exceeded 70% of the total number of applications submitted in each of these years. This is very encouraging as it indicates new families are aware of the help the Fund can provide.

**TABLE 1: Applications Submitted**

	FY 2014	FY 2015	FY 2016	FY 2017	FY 2018	FY 2001- 2018
<b>First-time applicants</b>	203	227	250	244	<b>223</b>	<b>3,591</b>
<b>Re-applicants</b> (first application received in a previous year or earlier that year)	80	78	72	103	<b>95</b>	<b>1,177</b>
<b>TOTAL applications</b>	283	305	322	347	<b>318</b>	<b>4,768</b>
% of applications received that were from families applying for the first time	72%	74%	78%	70%	<b>70%</b>	<b>75%</b>

CICRF staff is still in the process of determining whether families have met the eligibility criteria for 19% (60) of the applications submitted to the Fund in FY2018, which ended on 6/30/18. Of the applications submitted in FY2018 where the review is complete, 53% (138) were eligible and resulted in payments to the family to date. Another 25% (64) were determined ineligible because they did not meet the financial or residency criteria, while 22% (56) were never completed by the family or other resources were found.

## Families Receiving Financial Assistance in Fiscal Year 2018<sup>6</sup>

Unless otherwise indicated, the data below are based on the 190 families who received financial assistance from the Fund (“families served”) in FY2018.

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.

<sup>6</sup> For all FY2001-FY2018 charts, the total number of children is 2,204; for FY2018 charts, the total number of children is 190. All data are derived from the Massachusetts Department of Public Health Catastrophic Illness in Children Relief Fund database, 2018.

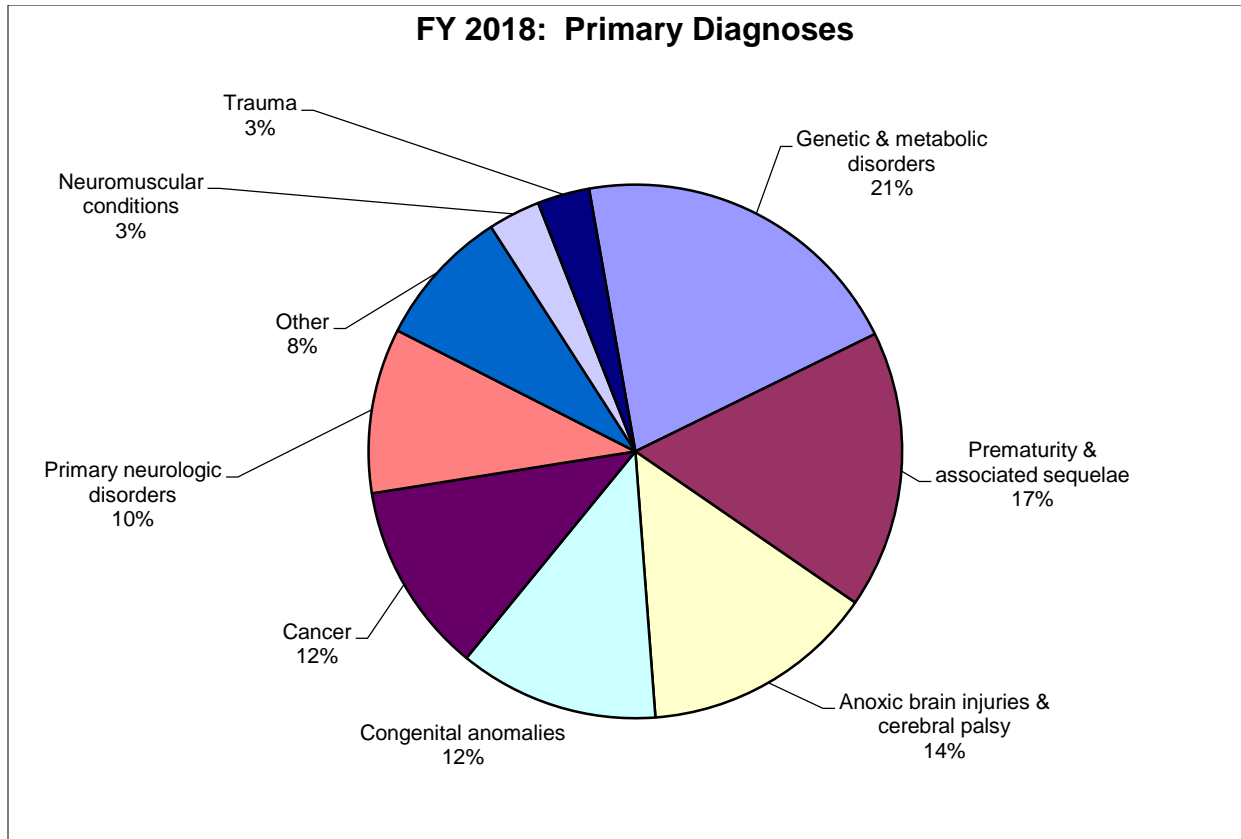
## Diagnoses

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. Often 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 chart on the next page summarizes the types of conditions of the children assisted by the CICRF in FY2018. The top six categories of conditions comprising 86% of the children supported by the Fund were genetic and metabolic disorders; prematurity and associated sequelae; anoxic brain injuries and cerebral palsy; congenital anomalies; cancer; and primary neurologic disorders. 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, in order to allow the child to live and participate fully in the community.

***“CICRF was an amazing resource for our family. When you have a child with complex medical needs who requires numerous hospitalizations, doctors’ appointments, and medical equipment, the monetary costs stack up. And not just the medical costs, but also gas money to and from appointments, hotel costs during hospital stays, and more. It causes even more added stress and difficulty to an already difficult time. To get reimbursed through this program, and to receive the help of staff members who walked us through what was expected of us, was invaluable.***

***- Recipient Family***



***“I cannot even begin to convey to you the relief I felt when told that this fund was accessible to my family. It is so difficult to find resources available to families like ours during good economic times let alone during a recession. We have always prided ourselves with working hard to provide our son with the things necessary to enable him to live as normal a life as possible, but I must confess it is becoming more and more difficult... From the bottom of my heart, I extend sincere thanks to all of you for the compassion and support that you so willingly offer to those of us who are in a position to call upon you.”***

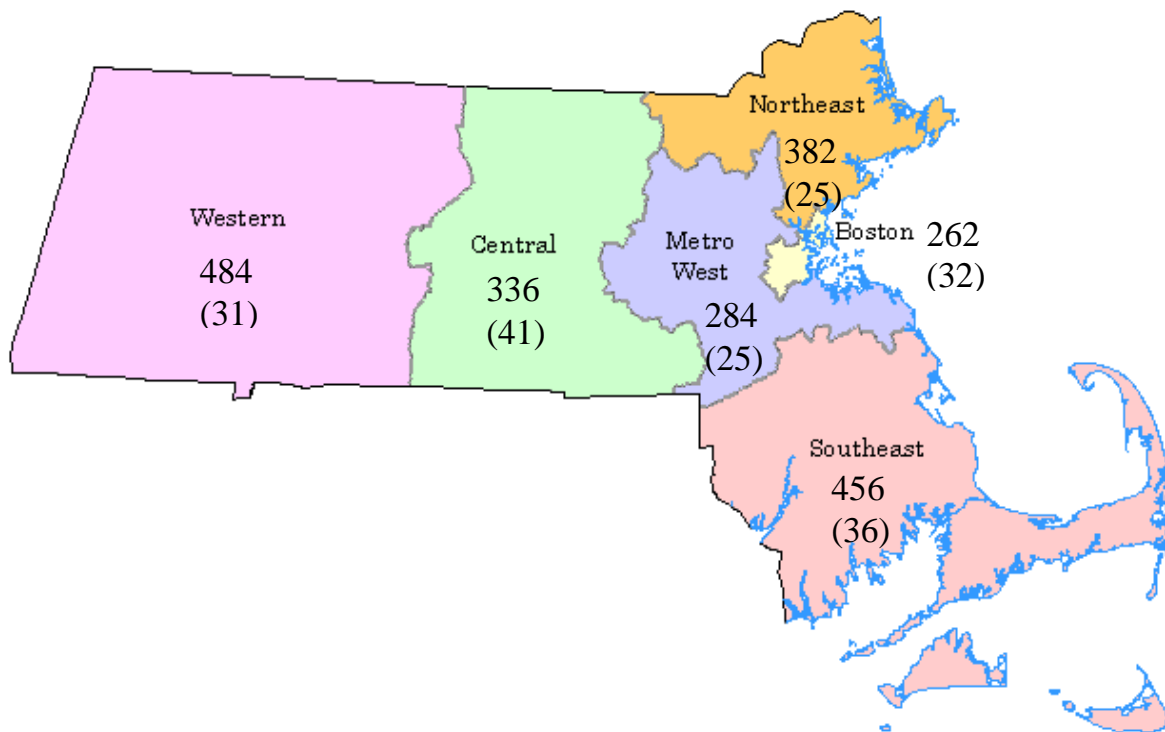
***- Recipient Family***

## 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. The majority of the children served is 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 in each region since the Fund's inception and for FY2018.

### Families Served Since Inception, and in FY 2018

The first number reflects the number of families served between FY2001 and FY2018, for a total of 2,204 families receiving reimbursement. The number below in parentheses is the number of families served in FY2018, for a total of 190 families.



## Age

The table below shows the breakdown of children’s age at time of application for the children reimbursed in FY2018. The average age was 7.6 years in FY2018.

Almost half (49.4%).of the children served in FY2018 were under age five. 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. 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.

**TABLE 2: Age at Time of Application**

	FY 2018	
	Number	Percent
Under age 1	36	18.9%
1 – 4 years	58	30.5%
5 – 9 years	29	15.3%
10 – 14 years	25	13.2%
15 – 18 years	29	15.3%
19 – 21 years	13	6.8%
Total	190	100.0%
Average Age	7.6 years	

*We are very thankful... for all your efforts in helping us through the process of applying to the CICRF for medical reimbursement. We know it took a great deal of time and effort to organize all the paperwork and details of our daughter’s case.*

*To the Commission members, thank you for listening to our story, realizing the importance of having all the dental work completed, and understanding the tremendous financial burden it created for our family.*

*We are so grateful for all your work and the generosity of the CICRF. [Our daughter] is smiling a lot and looking forward to...school where she knows she can make a difference in caring for others.*

*- Recipient Family*

**Race**

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

**TABLE 3: Families Served, by Race <sup>a</sup>**

	FY 2018	
	Number	Percent*
Hispanic/Latino/Black, Hispanic/Latino/White, Hispanic/Latino/Other	69	36.3%
White, non-Hispanic	64	33.7%
Black, non-Hispanic	29	15.3%
Multi-racial <sup>b</sup>	4	2.1%
Asian	7	3.7%
Other	10	5.3%
American Indian or Alaska Native	1	0.5%
Unknown	6	3.2%
Total	190	100.0%*

<sup>a</sup> 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.

<sup>b</sup> 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.

\*Percents may not total 100% due to rounding.

*“...I know how slim the budgets are and your assistance was invaluable. As I had written before, we had a very difficult and expensive year with [child’s name]...We are so grateful to you. I hope that I don’t have to contact you ever again, but it is nice to know you are there in case we have to... Thank you once again for all of your help throughout the years. Please thank everyone else who quietly save us and all the other catastrophic families.*

*- Recipient Family*

## Income Level

The CICRF provides assistance to families at all income levels, but the majority of families helped by the CICRF in FY2018 had low incomes with limited access to other resources. 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.

The federal poverty level (FPL) is a measure of family income that is calculated each year by the U.S. Department of Health and Human Services (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 U.S. Census Bureau.<sup>7</sup>

89.5% of families served in FY2018 had incomes under 300% of FPL. This is noteworthy, since MassHealth eligibility for children extends to 300% of FPL. In 2018, 300% of FPL was \$75,300 for a family of four.

**TABLE 4: Family Income, by Percent of Federal Poverty Level (FPL)**

% of FPL	FY 2018	
	Number	Percent*
≤ 200%	151	79.5%
201-300%	19	10.0%
301-400%	4	2.1%
401-600%	10	5.3%
601-800%	6	3.2%
>800%	0	0.0%
Total	190	100.0%*
Average income	\$33,667	
Median income	\$20,939	

\*Percents may not total 100% due to rounding.

<sup>7</sup> <http://aspe.hhs.gov/poverty/faq.shtml>.

## Insurance Status

All children assisted by the CICRF in FY2018 had health insurance.<sup>8</sup> Nevertheless, these families still had catastrophic medical or related expenses. Often this is because the insurance did not cover certain services or expenses, or because families have significant co-payments, co-insurance, or deductibles associated with care. Other times, the expenses were so great that families reached benefit limits and were left to cope with the rest of the expenses themselves. Fund staff makes 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 FY2018. Most families with private insurance had secondary state Medicaid (MassHealth) coverage in order to supplement their primary private insurance. 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. MassHealth Limited is emergency medical coverage for noncitizens 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), 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 conditions.

**TABLE 5: Primary Insurance**

Primary Insurance	FY 2018	
	Number	Percent*
MassHealth Standard	120	63.2%
Private/Other	61	32.1%
MassHealth Limited	8	4.2%
Medicare	1	0.5%
Total	190	100.0%
Number of privately insured with secondary MassHealth <sup>9</sup> coverage	54	
% with MassHealth as primary or secondary insurer	96.3%	

\*Percents may not total 100% due to rounding.

<sup>8</sup> 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.

<sup>9</sup> Includes MassHealth Standard, CommonHealth and Kaileigh Mulligan.



## 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 payment for medical and related services, such as co-payments and deductibles.

Table 6 shows the distribution of expense categories reimbursed in FY2018.

**TABLE 6: Expenditures by Service Category**

Service Category	FY 2018	
	Amount	Percent of total expenditures*
Family support	\$ 605,415	37.4%
Vehicle purchase	\$ 308,795	19.1%
Vehicle modification	\$ 308,785	19.1%
Previously modified vehicles	\$ 110,483	6.8%
Home modification	\$ 102,421	6.3%
Equipment and medical supplies	\$ 70,772	4.4%
Funeral expenses	\$ 46,633	2.9%
Medication	\$ 29,108	1.8%
Family travel & lodging (primarily related to out-of-state treatment)	\$ 21,187	1.3%
Medical expenses	\$ 11,579	0.7%
Insurance premiums (MassHealth, CommonHealth)	\$ 1,822	0.1%
Other	\$ 3,321	0.2%
<b>Total Expenditures</b>	<b>\$1,620,321</b>	<b>100.0%*</b>

\*Percents may not total 100% due to rounding.

Reimbursement of these expenses supports families caring 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 who need an accessible vehicle to transport their child to medical visits and elsewhere within the community.<sup>10</sup> The largest percent of funds

<sup>10</sup> Vehicle purchases and modifications are reimbursed according to a sliding scale based on income, and families have a lifetime limit on the total amount that the Fund will reimburse for these types of expenditures. The lifetime limit is also determined by a sliding scale.

reimbursed to families each year has been 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.

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 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.

### Reimbursements to Families

Total reimbursements to families in FY2018, and in all years since the creation of the Fund, are shown in Tables 7 and 8. From July 1, 2017 through June 30, 2018, the Fund reimbursed 190 families over \$1.6 million.

**TABLE 7: Reimbursements to Families**

	FY 2018	FY 2001 – 2018*
<b>Total</b>		
Minimum	\$ 60	\$ 30
Maximum	\$ 35,700	\$ 86,047
Average	\$ 8,528	\$ 13,125
Median	\$ 5,615	\$ 8,000
25 <sup>th</sup> percentile	\$ 3,656	\$ 4,672
75 <sup>th</sup> percentile	\$ 11,361	\$ 17,373
<b>Total # families</b>	<b>190</b>	<b>2,204</b>

\* FY2001-2018 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.

*“My daughter is 10 years old and has had 43 medical procedures and over 400 inpatient stays since birth ... CICRF has blessed my family with financial assistance to compensate for the years of financial difficulties while caring for a child with a catastrophic illness ... I had to make the choice to be a stay at home mom so I can care for and be the best advocate I could be ... When we had to upgrade to a larger vehicle to fit my daughter’s wheelchair, CICRF was able to assist in the large cost. Without these funds, I would not be able to do the life changing costly adaptations we need to make in order to cover all the extra medical expenses and give her an accessible life.”*

*- Recipient Family*

Reimbursable expenses are defined in the Fund’s policies set by the Commission and can change. The total amount reimbursed to families in a given year is not pre-defined. In general, if a family meets the eligibility criteria for the Fund, then CICRF reimburses the family according to the Fund sliding fee scale.<sup>11</sup>

**TABLE 8: Reimbursements to Families Since the Inception of the Fund**

	<b>Total Amount Reimbursed (\$)</b>	<b>Number of Families Receiving Assistance</b>	<b>Average Amount per Family (\$)</b>
<b>FY 2001</b>	63,062	2	31,531
<b>FY 2002</b>	70,861	13	5,451
<b>FY 2003</b>	1,144,335	121	9,457
<b>FY 2004</b>	3,108,764	303	10,260
<b>FY 2005</b>	1,219,532	186	6,557
<b>FY 2006</b>	1,437,730	187	7,688
<b>FY 2007</b>	1,180,503	139	8,493
<b>FY 2008</b>	1,699,299	211	8,054
<b>FY 2009</b>	2,277,800	261	8,727
<b>FY 2010</b>	2,561,725	286	8,957
<b>FY 2011<sup>12</sup></b>	1,946,417	248	7,848
<b>FY 2012</b>	1,467,282	171	8,581
<b>FY 2013</b>	1,993,984	197	10,122
<b>FY 2014</b>	1,634,726	163	10,029
<b>FY 2015</b>	1,780,983	182	9,786
<b>FY 2016</b>	2,056,724	210	9,794
<b>FY 2017</b>	1,663,413	171	9,728
<b>FY 2018</b>	1,620,321	190	8,528

*“I just want to let you know that there are not words to tell you that can communicate the gratitude I feel in my heart for this support. GRACIAS, GRACIAS, GRACIAS. Thank you and all the people that have been part of this process.”*

*- Recipient Family*

<sup>11</sup> 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.

<sup>12</sup> 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.

#### **IV. REVENUE AND EXPENDITURES**

Until December 31, 2013, the CICRF was funded by quarterly transfers made from the Medical Security Trust (MSTF), if funds were available after other obligations of the MSTF were met<sup>13</sup>. As of January 1, 2014, the funding mechanism was changed to the Commonwealth Care Trust. As before, the funding continues to come from employers' contributions.<sup>14</sup>

During the Fund's initial years of service, there were significant remaining funds at the close of each fiscal year, as the Fund was still fairly unknown and underutilized. As knowledge and utilization of the Fund increased, the expenditures increased to match the need. When the Fund had a large balance, the Commission discussed how much of a balance was desirable and agreed that there should always be at least one year's reserve on hand since the amount of transfers into the Trust each year is unknown and not guaranteed.

Due to the economic downturn and the resulting shortfall in the MSTF, there were no transfers from the MSTF to the CICRF from the 4<sup>th</sup> quarter FY2009 through FY2013. This was of tremendous concern. While the CICRF Trust was able to support the program in FY2010 and FY2011 (due to a surplus in previous years and policy changes made in FY2010 to reduce expenditures), the balance in the Fund dropped to under \$900,000 by the end of FY2011. Spearheaded by Senate President Therese Murray, the legislature allocated funds from the Health Safety Net administration account in FY2012 and FY2013 to supplement CICRF Trust funds so the program could remain in operation. By the end of FY2013, the CICRF Trust balance had fallen to \$15,507, and in FY2014 the legislature included an earmark in the Department of Public Health administration account for the CICRF. Without these actions the program would not have survived.

Regular transfers from the MSTF resumed in FY2014. Since then, the CICRF has begun to replenish and no supplemental funds have been needed. As noted above, the MSTF was abolished at the end of 2013, and the funding mechanism for the CICRF was changed to the Commonwealth Care Trust. Transfers to the CICRF Trust have been consistent since FY2014.

In FY2018, four transfers were made into the CICRF Trust. Total deposits (transfers plus interest) were approximately \$3.1 million, while total expenditures for payments to families, staffing and other expenses were \$2.3 million. FY2018 ended with a healthy balance of \$5.3 million.

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

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<sup>13</sup> 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.

<sup>14</sup> 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**

	<b>Balance from Prior Fiscal Year (\$)</b>	<b>Deposits (includes interest) (\$)</b>	<b>Expenditures (includes administrative costs) (\$)</b>	<b>Balance Forward to Next Fiscal Year (\$)</b>
<b>FY 2001</b>	--	2,762,950	63,062	2,699,888
<b>FY 2002</b>	2,699,888	2,519,271	120,149	5,099,010
<b>FY 2003<sup>15</sup></b>	5,099,010	720,771	1,208,507	4,611,274
<b>FY 2004<sup>15</sup></b>	4,611,274	47,260	3,171,764	1,486,769
<b>FY 2005</b>	1,486,769	2,606,336	1,242,563	2,850,541
<b>FY 2006</b>	2,850,541	2,799,303	1,489,261	4,160,584
<b>FY 2007</b>	4,160,584	2,845,088	1,292,183	5,713,488
<b>FY 2008</b>	5,713,488	2,841,943	1,819,146	6,736,284
<b>FY 2009<sup>15</sup></b>	6,736,284	2,070,541	2,487,524	6,319,302
<b>FY 2010<sup>15</sup></b>	6,319,302	23,293	3,051,570	3,291,025
<b>FY 2011<sup>15</sup></b>	3,291,025	16,066	2,425,395	881,695
<b>FY 2012<sup>15,16</sup></b>	881,695	2,098	639,952	243,842
<b>FY 2013<sup>15,16</sup></b>	243,842	572	228,907	15,507
<b>FY 2014<sup>16</sup></b>	15,507	3,323,428	615,421	2,723,515
<b>FY 2015</b>	2,723,515	2,903,247	2,233,697	3,393,064
<b>FY 2016</b>	3,393,064	3,033,103	2,612,305	3,813,862
<b>FY 2017</b>	3,813,862	3,046,230	2,286,280	4,573,812
<b>FY 2018</b>	4,573,812	3,075,178	2,328,516	5,320,473

<sup>15</sup> During FY2003, FY2004, and from FY2009-FY2013 the Fund did not receive the full amount 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 4<sup>th</sup> quarter FY2013 transfer was made in early FY2014.

<sup>16</sup> 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 many 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 18 years and is hopeful it will be able to continue to serve families in need.

*“... The support that the CICRF provided us with truly changed our lives.*

*Speaking before your group about our family’s circumstances and hearing the responses of the board members was an incredibly validating experience. It was the first time the totality of our family’s stresses and health issues were heard and understood. This was a huge psychological boost after months of relentlessly advocating with insurance companies and various agencies for services and reimbursements. The financial security the CICRF restored to us enabled me to go back to work after two years; and I’m not sure if I would have ever come back had I stayed out of work any longer.*

*We are grateful every single day for the children’s recovery, and won’t ever forget the support this program provided us. Thanks to each and every one of you for thinking “outside the box” when considering our family’s needs.”*

*- Recipient Family*

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*As of January 2019*

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