

How Ronald McDonald House Charities of Rochester, NY (RMHCR) is helping to create a *Healthier New York*

-Testimonial to Joint Legislative Budget Committees – Scheduled for 1/23/24

We are so grateful for the opportunity to provide a testimonial to the Joint Legislative Budget Committees. RMHCR is 90% philanthropically funded by individuals, businesses, and foundations in the Greater Rochester Area. Enhanced reimbursement to support RMHCR's work would allow us to expand our impact for *A Healthier New York*. We are proud to share some of the ways we are innovating to address health inequities for New York State families.

RMHCR facilitates access to world-class pediatric and obstetric healthcare for NY State's low-income, vulnerable, and at-risk families—by providing a place for parents, caregivers, and other key family members of critically ill or injured children, **and high-risk pregnant mothers**, of all races and ethnicities, to lodge for free at the point of treatment (within Rochester's hospitals) or minutes away—enabling access to life-saving and Family Centered Care (FCC) shown to improve health outcomes including faster recovery times, improved patient and family experience, and reduced cost. (Source: <https://journalofethics.ama-assn.org/article/patient-and-family-centered-care-its-not-just-pediatrics-anymore/2016-01>).

In 2023, RMHCR provided 8,500 nights of lodging within or next to the hospital, served 3,000 family members, provided 35,000 encounters, and saved families over \$2,000,000.

95% of the families we serve are from New York State and the majority (57%) are Medicaid recipients and fall into the low-income category. Without our services, many families would incur significant financial debt, have nowhere to stay, or forego care altogether.

Sadly, non-medical expenses associated with having a hospitalized child are prohibitive to many and can lead to delaying or even foregoing care for children. In America, medical bills are the most common reason for bankruptcy. In fact, medical bankruptcy statistics suggest that 17% of adults with healthcare debt had to declare bankruptcy or lose their home because of it as of 2022.

While America already has the most expensive health care of any country, prices are trending upward. Projections by the Centers for Medicare and Medicaid Services (CMS) estimate that healthcare expenditures will reach approximately \$6.2 trillion in 2028, a 50% increase from 2020.

- *The average age of a medical bankruptcy filer is 44.9 years old.*
- *40% of Americans fear they won't be able to afford health care in the upcoming year.*
- *17% of adults with health care debt declared bankruptcy or lost their home because of it.*
- *66.5% of bankruptcies are caused directly by medical expenses, making it the leading cause for bankruptcy.*

- *As of April 2022, 14% of Americans with medical debt planned to declare bankruptcy later in the year because of it.*

In New York State, families living in poverty disproportionately include Black, Native Hawaiian, and other Pacific Islander and American Indian families. These families are 20 percent or more likely to experience poverty than their white counterparts (Office of the New York State Comptroller, Dec. 2022) and therefore more likely to be negatively impacted by non-medical expenses are economic barriers to healthcare. We know from data collected directly from our families—via surveys families are asked to complete upon checkout—that without RMHCR, many would delay or forego care.

RMHCR uses health outcome data from the Finger Lakes Performing Provider System, Common Ground Health, University of Rochester Medical Center, Rochester Regional Health, and Monroe County Department of Public Health to identify the most critical community needs. This in conjunction with area thought leaders and community health partners informed RMHCR's strategy and identified opportunities for innovation to meet these needs. The following next-generation primary care approaches address these significant areas of need: **promoting healthy women, infants, and children; creating access to mental health support; and continuum of care** supportive services via a mobile unit.

RMHCR is committed to addressing the aforementioned areas by providing seamless support of programs and services in collaboration with our healthcare partners at UPMC and RRH.

RMHCR Intervention

As a community-based organization delivering supportive programs and services to families with critically ill or injured children or high-risk pregnant mothers, in conjunction with our healthcare partners, we are successfully impacting the quintuple aim:

1. **Increasing Quality** – by eliminating barriers, RMHCR enables access to life-saving and Family Centered Care (FCC), which has been shown to improve health outcomes including faster recovery times, improved patient and family experience, and reduced cost. (Source: <https://journalofethics.ama-assn.org/article/patient-and-family-centered-care-its-not-just-pediatrics-anymore/2016-01>).
2. **Decreasing Cost** –RMHCR enables access to timely care for reduced length of patient stay and avoidance of patient bounce back—alleviating visits to hospital emergency departments and freeing up hospital beds. RMHCR decreases costs for the healthcare system and for the families we serve. The non-medical cost burden to families, which includes lost earnings plus expenses, is considerable among families of children who are hospitalized, according to a study published online Aug. 13 in *Pediatrics*. "Non-

medical costs place burdens on families of children who are hospitalized, disproportionately affecting those with competing socioeconomic challenges," the authors write. (Source:

<https://publications.aap.org/pediatrics/article/142/3/e20180195/38669/Lost-Earnings-and-Nonmedical-Expenses-of-Pediatric?autologincheck=redirected>).

3. **Enhancing Family Experience** – A child’s hospitalization is a source of anxiety, depression, and stress for parents. RMHCR provides a place of lodging, respite, and safety for families, with access to interventions to help parents experience less stress and enable them to participate in a child’s medical care. RMHCR removes the non-medical costs associated with having a child in the hospital, known to exacerbate financial and emotional stress. In addition to free lodging, meals, and transportation, we provide referrals, private trauma-centered yoga, education resources about diagnoses and treatments, a fitness room, and an organic support system with our staff and with other families.
4. **Reducing Clinician Burnout** – Now more than ever, clinicians are experiencing burnout. By helping to improve throughput by supporting families, which leads to reduced length of stay and avoidance of readmission, RMHCR is reducing the burden on clinicians, allowing them to remain focused on their clinical work while we fill in the gaps with our services.
5. **Addressing Inequity** – RMHCR removes systemic barriers to care. For patients in poverty, the inability to rely on transportation or financial instability hinders their ability to engage with the health ecosystem. (source: <https://nationalhealthcouncil.org/blog/limited-access-poverty-and-barriers-to-accessible-health-care/>). Low-income families are disproportionately at risk due to social determinants of health and lack of financial resources. “The effects of child poverty on health are pervasive. They start from the moment a child is born and continue throughout the lifespan. Children from low-income families and neighborhoods are more likely to be born at a lower birth weight, suffer a greater rate of infant mortality, and experience setbacks in areas like language development, chronic illness, environmental exposure, nutrition, and injury.” (Source: <https://www.urmc.rochester.edu/childrens-hospital/news/child-poverty-reduction-act.aspx>.) RMHCR steps in to meet families where they are—despite income level, social status, and/or race—and removes the financial burden of lodging, food, transportation, and more. Providing all for free to families with a critically ill or injured child or a high-risk pregnant mother.

RMHCR is aligned with the 2022-2024 Monroe County Joint Community Health Needs Assessment and Community Health Improvement Plan (a collaborative report from the Community Health Improvement Workgroup which is managed by the Center for Community Health & Prevention and includes several community partners—this report serves UR Medicine, Rochester Regional Health and the Monroe County Department of Public Health) that identified areas where Monroe County health indicators were worse than the state. After extensive community engagement, the following two areas were selected as the main health challenges of focus for the CHNA/CHIP 2022-2024:

- **Goal 1: Promote Healthy Women, Infants, and Children**
 - Objective 1: Reduce racial, ethnic, economic, and geographic disparities in maternal and child health outcomes, and promote health equity for maternal and child populations.
 - **RMHCR intervention:** RMHCR has provided over **700 nights of free lodging within or next to the hospital to high-risk pregnant moms. The average length of stay was 17 nights, and the longest stay was 102 nights.** RMHCR has close referral partnerships with OBGYN practices serving pregnant mothers facing racial barriers to health, especially black mothers who experience a severe maternal morbidity rate in Monroe County—more than double that of white mothers. Referred high-risk pregnant mothers of all races and ethnicities lodge with us for free, for as long as they need, next door to Strong Memorial Hospital to be close to care for better maternal and fetal outcomes. This lodging includes nutritious meals, social-emotional support, and free classes with Strong Beginnings (RMHCR covers the cost of classes on breastfeeding, childbirth, and newborn care). It also helps to prevent the transfer of fragile newborn babies from rural hospitals. Included as referring partners and on our Medical Advisory Board is Dr. Eva Pressman, Chair of the Department of Obstetrics and Gynecology at the University of Rochester, a specialist in high-risk pregnancies. Also, on the RMHCR Medical Advisory Board, and Board of Directors, is Dr. Lauralei Thornburg who specializes in high-risk pregnancies. Their guidance and the close referral partnerships RMHCR has with their practices, ensure we are reaching mothers experiencing racial inequities and Black mothers who face severe maternal morbidity rates in Monroe County (more than twice that of White mothers).
- **Goal 2: Promote Well-Being to Prevent Mental and Substance Use Disorders**
 - Objective 2:1: Strengthen opportunities to build well-being and resilience across the lifespan.
 - Objective 2:2: Facilitate Supportive Environments to promote respect/dignity for all ages.

- **RMHCR Intervention: In 2023, RMHCR provided 484 nights of lodging to families with a child who had a mental health diagnosis. This includes 384 nights for eating disorders and 79 for other psych diagnoses.** In addition, to providing lodging for families dealing with pediatric mental health issues, RMHCR offers a Mental Health and Wellness Family room—the first space in the Ronald McDonald House national network dedicated entirely to families with children receiving mental health services. Prior to opening, families with children in the partial hospitalization programs and inpatient units tell of waiting in their cars for hours—with no space for respite in the clinical environment. In 2024, URMHCR will be opening the region’s first-ever psychiatric urgent care clinic for youth. The Brighter Days Pediatric Mental Health Urgent Care Center will be located at Golisano Children’s Hospital next to Ronald McDonald House Charities of Rochester’s Mental Health & Wellness Family Room. RMHCR’s dedicated space will run in partnership with the Division of Child & Adolescent Psychiatry to support the needs of families when they encounter mental health challenges. We will provide a place for families with a child in treatment for a mental health diagnosis to find respite, educational and referral resources, companion support, healthy food, laundry, and computer access.
- **RMHCR Interventions:** Research shows the prevalence of PTSD among parents of critically ill children is high and significantly different. Therefore, it is crucial to focus on this vulnerable group, providing them with essential psychological counseling and comprehensive social support to reduce the occurrence of PTSD.” (Source: Journal of Affective Disorders). A child’s hospitalization is a source of anxiety, depression, and stress for parents. RMHCR provides a place of lodging, respite, and safety for families, with access to interventions to help parents experience less stress and to enable them to participate in a child’s medical care. We keep families together when they are in crisis, to reduce trauma. We also remove the non-medical costs associated with having a child in the hospital, known to exacerbate financial and emotional stress. In addition to enabling access to medical care and treatment by providing free lodging, meals, and transportation, we provide mental health and wellness support via referrals, private trauma-centered yoga, education resources about diagnoses and treatments, a fitness room, and an organic support system with our staff and with other families.

Our 3 lodging sites allow us to house **33 families a day 365 days a year** and includes our House Within the Hospital (HWTH) serving Golisano Children’s Hospital (with the only Pediatric Cardiac Surgeon in the region). This is the only HWTH in NY and 1 of only 19 nationally. Our

Family Rooms in Rochester's hospitals offer free food, respite areas, laundry & showers so our families can rest and be nourished.

We are also in the planning phases of our ***House to Home Program***, a mobile unit, to act as a care coordinator, utilizing supportive services by telemedicine visits as required and biannual comprehensive interdisciplinary care management service for families as a supplement to the primary care medical home. Children identified in the top tier of medical complexity will be given one-hour interdisciplinary care planning appointments twice a year. Currently, participants would include the primary care pediatrician, CMC medical provider, CMC nurse case manager, home nurse representative, guardian as well as care coordinator, social worker, home health manager, pharmacist, nutritionist, and other pediatric specialists as deemed appropriate. The *RMHCR House to Home Program* is intended to augment this level of care post-discharge.

The *House to Home* Complex Pediatric Care Team is an interdisciplinary project team. They are based out of Golisano Children's Hospital and also support Complex Pediatrics Care for Rochester Regional Health, the second largest healthcare system in this region. This team will manage all data coordination/dissemination to subspecialty/primary care offices and provide the scheduling of care and coordination for children with chronic and complex medical and social conditions to decrease the cost of care by decreasing hospital admissions/length of stays, emergency room visits, duplication of tests and treatments, enhancing patient compliance with treatment plans, and enhancing communication between subspecialists and the primary care medical home. Together we will also measure patient, family, referring physician, and specialist satisfaction.

The *House to Home* program is predicted to save healthcare costs based on Golisano Children's Hospital Pediatric Practice reflecting national data showing 30% of the time (and healthcare dollars) is spent caring for the top 1% of complex children.

RMHCR's important work is almost entirely (90%) funded by philanthropy. RMHCR needs enhanced reimbursement to support this work and integrate primary care with organizations like RMHCR that can address social drivers of health.

RMHCR would like to express gratitude and appreciation to CMS and the Department of Health and Human Services for approving New York's request to amend Medicaid section 1115. This foresight and commitment to serve populations most vulnerable and at risk, is commendable; and as funds are allocated, we hope RMHCR is seriously considered as a recipient. Enhanced reimbursement will expand RMHCR's impact on health equity for New York State families for a *Healthier New York*.