**Catastrophic Illness in Children Relief Fund Commission**

**Open Minutes**

**April 3, 2024**

The meeting was called to order by the Chairperson J. Prontnicki at 9:33 a.m.

J. Prontnicki announced that in compliance with the New Jersey Open Public Meetings Act, the specifics as to time and place of this meeting were sent to the Office of the Secretary of State and the Department of Personnel for filing and posted on the official bulletin boards provided by those offices for notice of public meetings. Also, notices were prepared for two newspapers to inform the public of this meeting.

J. Prontnicki conducted a roll call of members as follows:

**Present:**

Janice Prontnicki, Chairperson

Phyllis Shanley Hansell, Vice Chairperson

Kidanemariam Meshesha

Manuel Paulino

Anthony Valenzuela

Howard Weinberg

Michael Young (for Adam Neary)

**Absent:**

Jeffrey Carrick

Ralph Condo

Carl Underland

**Guest:**

Caroline Gargione, DAG

**Staff:**

Christian Heiss, Executive Director

LorieAnn Wilkerson-Leconte, Deputy Executive Director

Amy Taklif, Senior Analyst

Janet Valentin-Forte, Secretary to the Commission

**Adoption of Agenda:**

J. Prontnicki made a motion to adopt the proposed meeting agenda for the April 3, 2024 meeting. The motion passed unanimously.

**Public Comments:**

None.

**Approval of Minutes of February 2024 Meeting:**

J. Prontnicki made a motion to approve the open meeting minutes from February 7, 2024, as presented. The motion was adopted with 6 votes in favor. M. Young abstained due to absence from the meeting.

J. Prontnicki made a motion to approve the closed meeting minutes from February 7, 2024, as presented. The motion was adopted with 6 votes in favor. M. Young abstained due to absence from the meeting.

**Treasurer’s Report:**

C. Heiss reported that the Commission will review 36 applications, including 27 eligible, 6 ineligible, and 3 reconsiderations, with potential payments totaling $1,063,828.01.[[1]](#footnote-1) There is an estimated $20 million in the Catastrophic Illness and Children Relief Fund which is sufficient to cover the applications being heard at this meeting. $8.3 million are remaining in the fiscal 2024 budget after all payments for today's commission meeting are made.

C. Heiss stated that since the pandemic, approximately half of the funds budgeted for grants on behalf of applicants to the Fund have been used each year, with approximately $4 million going into our reserves every year. The State Office is investigating strategies to better distribute the budgeted funds to families by examining recent policy changes that may increase disbursements. The State Office is also boosting outreach efforts to increase application volume. After today’s meeting, with only one meeting left in FY24, we will have $4.6 million in our Family and Provider Budget. The State Office budget contains $2.5 million, with $1.39 million available.

**Fund Operation’s Report:**

Since July 1, 2024, the State Office received 268 applications. Currently, staff are processing 118 applications and there are 19 unassigned applications. The oldest application was received on August 4, 2023.

**Executive Director’s Report:**

C. Heiss stated that L. Wilkerson-Leconte met with Jarek Muchowski, Senior Business Advisor for the Virginia State Director of Medicaid to provide technical support for their medical debt relief program. He also highlighted that the Department of Human Services (DHS) has established an Operations Council—an open working group to identify cross-division issues and coordinate potential solutions—and invited the State Office to join. C. Heiss and L. Wilkerson-Leconte attended the inaugural meeting on February 29, 2024

L. Wilkerson-Leconte provided additional details regarding the meeting with the State of Virginia, Office of Medicaid. The State of Virginia reached out to the State Office to learn about our operational practices, as they have recently received state funding to establish their own fund that deals with catastrophic illness debt. L. Wilkerson-Leconte and Fiscal Manager J. Fallucca met with the Virginia team to assist them with creating a strong budget proposal to secure additional funding for their program.

**Outreach Report:**

L. Wilkerson-Leconte recognized A. Taklif for leading the State outreach efforts, which has generated a surge in requests for presentations and likely, an uptick in applications. The State Office will be able to track outreach impact with the new application upgrade.

L. Wilkerson-Leconte updated the Commission regarding the Spring Family event. Given feedback from last year’s family event, families felt strongly that a future event should take place on a weekend day, instead of a weekday at any time. To ensure maximum participation from families and the Commission, the State Office set the date for Sunday, June 9th, 11 am to 2:30 p.m. The State Office also received feedback that instead of one family event for the year in Mercer County, there should be regional events throughout the year, therefore the Spring Family event will be held in northern New Jersey, a Summer event in the southern region, and a winter event in Mercer County. L. Wilkerson-Leconte proposed two venues for the Commission’s consideration – the West Side Community Center and Montclair State University. P. Hansell Shanley suggested the Montclair Art Museum. The Commission agreed to leave the decision-making to the Chair and Vice-chair, along with the State Office leadership.

**Closed Session:**

At 9:57 a.m., J. Prontnicki made a motion to go into the closed session to review applications. The motion passed unanimously.

**Review of Applications:**

**Eligibles:**

J. Prontnicki made a motion to approve the eligible applications, as presented. The motion passed unanimously.

**Reconsiderations:**

J. Prontnicki made a motion to approve the reconsidered applications, as presented. The motion passed unanimously.

**Ineligibles:**

J. Prontnicki made a motion to approve the ineligible applications, as presented. The motion passed unanimously.

J. Prontnicki noted that in closed session, the Commission asked the State Office staff to review policy criteria and precedents regarding the way the Fund reimburses for room and board for the child/patient, as well as travel expenses for the family visiting the child, and to report the findings at the next Commission meeting for review.

**Unfinished Business:**

C. Heiss discussed raising caps for home modifications, speech, language, hearing and ABA therapies to allow for more reimbursement to families. C. Heiss stated that N.J.A.C. Chapter 155 expires on May 21, 2025, creating an opportunity to include the changes. J. Prontnicki suggested that the Bylaws Committee and Legislative Committee review the prospective changes and determine whether to include them in the re-adoption process that is due to be completed around September 2024 for timely review prior to publication in the New Jersey Register.

C. Heiss also noted that the annual committee meeting reports are due prior to the end of the fiscal year at the end of June. New commissioners will be assigned to a committee that fits best with their expertise, so all committees can meet and prepare their annual committee reports. P. Shanley Hansell has agreed to chair the Bylaws Committee. J. Prontnicki stated that she will advise R. Condo, the Chair of the Legislative Committee, to work closely with the Bylaws Committee to present a report of proposed changes in caps for Home Modification and the aforementioned therapies.

**New Business:**

H. Weinberg suggested that the Commission discuss current residency requirements that allow reimbursement for out-of-state medical expenses for applicants who move to New Jersey. He would like to re-visit that eligibility requirement to be sure the Fund does not pay for those expenses for families that may potentially be staying here solely for that benefit. H. Weinberg would also like to revisit the out-of-network policy to discuss if elective inpatient procedures should be reimbursed by the Fund. C. Heiss offered to analyze data to provide more context to H. Weinberg’s questions. C. Heiss clarified that the current out-of-network policy is geared toward not allowing ambulatory out-of-network expenses where the child’s insurance does not allow for the use of out-of-network providers. J. Prontnicki asked the State Office to do some research and find out how often the Commission paid for those types of expenses and how often the expenses happen with minor surgeries vs. major surgeries, specifically elective surgery. C. Heiss will provide the analysis to be reviewed and discussed in the next Commission meeting.

J. Prontnicki made a motion to adjourn the meeting. All Commission members voted in favor. The meeting adjourned at 11:15 a.m.

1. After Commission action and revision of a family responsibility miscalculation (discussed in the closed minutes), net payable expenses for this meeting totaled $1,069,569.75. [↑](#footnote-ref-1)