

STATE OF WEST VIRGINIA DEPARTMENT OF HEALTH AND HUMAN RESOURCES James "Tiger" Morton Catastrophic Illness Commission

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Honorable Members of the West Virginia Legislature 1900 Kanawha Boulevard, East Charleston, West Virginia 25305

Members of the Legislature:

The James "Tiger" Morton Catastrophic Illness Commission (Commission) was created during the 1999 regular session of the West Virginia Legislature to act as a last resort for those in dire need of medical assistance during a life-threatening illness once all other resources are exhausted. The Commission's 2021 Annual Report is enclosed for your review.

The Commission's funds are at critically low levels which required the Commission to start a waitlist in November 2019 for new applicants due to the anticipated obligations for current clients. The waitlist was lifted in October 2021. Over the past six years, the Commission has received an annual allocation of approximately \$100,000 to cover personal services, with any unused balance transferred to a special revenue account to assist eligible clients with medical treatment and travel and to pay operational expenses. With changes enacted by the Legislature through SB 2011 during the 2021 second extraordinary session that amended how the allocated funds are distributed, the Commission is concerned the balance can no longer be transferred to the special revenue fund. The Commission's funds are projected to be exhausted during state fiscal year 2023 as client obligations are expected to exceed the available cash balance.

The Commission is committed in its efforts to continue assisting West Virginians with catastrophic illnesses who are without other resources to enable them to receive the life-saving treatment they need.

Jacques R. Williams, Esq.

Chair

Julie C. Palas, J.D.

Executive Director

James "Tiger" Morton Catastrophic Illness Commission 2021 Annual Report

Since 2000, the James "Tiger" Morton Catastrophic Illness Commission (Commission) has provided lifesaving interventions to more than 1,650 West Virginians. The Commission is a last resort for those in dire need of medical assistance where the risk of death is imminent and no other resources exist. Six Commissioners are appointed by the Governor and include a doctor, lawyer, social worker, nurse and two citizens at-large.

The Commission makes direct payments to providers through the West Virginia Department of Health and Human Resources' Medicaid program, administered by the Bureau for Medical Services, for individuals who are not eligible for Medicaid benefits yet cannot afford to pay costs associated with catastrophic illness. Many West Virginians live just above the federal poverty level; they cannot afford insurance and are not eligible for state assistance.

The Commission's Executive Director consults with the Bureau for Medical Services and hospital charity care programs to determine if applicants are eligible for those programs. Before receiving assistance from the Commission, an eligible applicant must apply for and be denied coverage by Medicaid and attempt to obtain health insurance coverage through the Marketplace (healthcare.gov) or private insurance options.

Assistance provided by the Commission includes lifesaving medical treatments and related travel costs. Assistance is capped at \$200,000 for medical services and \$5,000 for transportation costs. Examples of covered expenses include:

- Proven and accepted medical procedures, such as surgery, organ transplants, and chemotherapy;
- Medication that prevents rejection after a transplant and/or recurrence of a lifethreatening illness; and
- Gasoline, lodging, airfare, and car rental costs to medical facilities for patients to receive treatment or for related medical appointments.

Through direct financial assistance and referrals to other programs, the Commission assisted 35 individuals in calendar year 2021. Partnering programs include the American Cancer Society, Angel Flight, hospital financial counselors, regional community action agencies, hotels with discounts for medical treatment, and local cancer assistance programs. Prescription drug discounts and online medical copayment assistance were also utilized. By working with these partners and available resources, the Commission leverages additional funds for client assistance services.

A key objective of the Commission is to leverage scarce resources for maximum benefit. An example of leveraging can be seen in the Commission's historical data: for every dollar billed to the Commission for providing lifesaving care of a West Virginia resident, the Commission pays only 20-25 cents by paying at Medicaid rates. Not only does the Commission save lives, but it saves money.

Examples of continuing assistance provided in 2020 and 2021:

- 42-year old male with stage 4 colon cancer; provided travel assistance
- 47-year old female with stage 4 liver disease; provided supplemental coverage for transplant
- 57-year old female with lymphoma received medical treatment and travel assistance
- 50-year old female with lung and throat cancer received transportation for treatment
- 66-year old female with breast cancer received treatment
- 60-year old male with heart, liver, and kidney failure received medical treatment
- 62-year old male with brain and lung cancer received medical treatment

General revenue funds of \$105,695 were allocated to the Commission by the West Virginia Legislature for personal services in SFY 2020 and again in SFY 2021, with the balance being used for clients' medical assistance, related travel expenses, and operational expenses. The balance is not enough to pay the total amount of medical assistance needs annually. With the changes in allocated funds for SFY 2022, the balance will no longer be transferred to the Catastrophic Illness Fund.

The number of applications for assistance decreased by half in 2020, slowing when clinics and hospitals stopped referring patients due to the waitlist; however, the dollar amount of medical claims received by the Commission did not decrease until 2021, as demonstrated in the chart below.

James "Tiger" Morton Catastrophic Illness Commission Financial Snapshot: SFY 2019, 2020 and 2021									
Medical Claims Received from Providers	2019 \$1,361,486 (approx.) 2020 \$1,386,770 (approx.) 2021 \$154,377 (approx.)	increase of 100% from 2018 (was \$677,365) increase of 1.85% from 2019 decrease of 89% from 2020							
Medical Claims Paid by Medicaid on behalf of the Commission*	2019 \$282,964 (approx.) 2020 \$235,726 (approx.) 2021 \$60,200 (approx.)	increase of 60% from 2018 (was \$176,638) decrease of 83.3% from 2019 decrease of 25.5% from 2020							
Travel Costs Paid by the Commission	2019 \$13,191 (approx.) 2020 \$15,898 (approx.) 2021 \$4,579 (approx.)	decrease of 244% from 2018 (was \$32,253) increase of 21% from 2019 decrease of 71.5% from 2020							

^{*}Payment amounts do not include outstanding claims returned for corrections.

Since October 1, 2015, the Commission has reduced operational costs as the Executive Director assumed the additional duties as the Executive Director of the West Virginia Women's Commission. Salaries and office expenses are shared equally, and the Commission continues to consider measures to further reduce operational costs.

As a 170(c)(1) government entity for a charitable public purpose, the Commission can accept tax-deductible contributions, gifts, property, and grants from both private and corporate donors. A strategic fundraising campaign includes requesting increased funding from the Legislature and approval to share in various collected state fines and fees. To date, requests to multiple foundations and charitable organizations were made without any success. A concern expressed by many of those approached was a reluctance to expend scarce resources to a public entity or their criteria giving did not include public entities. Accordingly, it

appears to the Commission that the core of future fundraising will have to come from budgetary resources, such as legislative appropriations or collected state fines or fees as recommended in the 2004 legislative audit as a line entry on state tax returns. The Commission will continue to provide educational presentations and materials at conferences, outreach events, and online to increase awareness about the Commission's services for West Virginians with life-threatening illnesses.

The chart below identifies by county West Virginians who received both in-kind assistance and financial assistance from the Commission in 2019, and those who received in-kind assistance (37) or were waitlisted (34) for assistance in 2020, and those who received in-kind assistance (25) or were waitlisted/covered (10) for assistance in 2021. The numbers continued to decline as the waitlist stayed in effect until October 2021; however, the numbers are expected to increase in 2022. The numbers also do not include West Virginians the Commission continues to assist from previous years (17) or applications taken after December 2021. Additional applications taken during December 2021 could add 3 clients, thus bringing the total for 2021 to 38.

Catastrophic Illness Commission Clients: Calendar Years 2019, 2020 and 2021 -to show decline of referrals when waitlist was in effect

County	2019	2020	2021	County	2019	2020	2021	County	2019	2020	2021
Barbour	3	1		Kanawha	14	10	4	Pleasants			1
Berkeley	4	1		Lewis	1			Pocahontas	1		
Boone	1	1	2	Lincoln	1	2		Preston	1		
Braxton		1		Logan	3	2		Putnam	5		1
Brooke	2		1	Marion	3		1	Raleigh	15	3	8
Cabell	3	2		Marshall	2			Randolph	3	3	
Clay	1	1		Mason	2	3		Summer s	2	1	1
Fayette	6	6	2	Mercer	1	4	3	Taylor	1		
Grant	1	1	1	Mineral	1			Tyler		1	
Greenbrier	5	2		Mingo	2	2	1	Upshur	1		
Hampshire	2			Monongalia	4	4	1	Webster	4	1	
Hancock	2	1		Morgan		1		Wetzel	2		
Hardy	4	1		Monroe	6			Wood	7	1	
Harrison	12	3		Nicholas	4	1	2	Wyoming	3	2	
Jackson	2		2	Ohio	1	1		Unknown	7	7	4
Jefferson	2	1		Pendleton	1			TOTAL	148	71	35

James "Tiger" Morton Catastrophic Illness Commission Members

Jacques Williams, Attorney, Chair, Monongalia County
Sandra Cotton, Registered Nurse, Monongalia County
John Davidson, Jr., Member-at-Large, Kanawha County

Patricia Davis, Member-at-Large, Hampshire County
Frances Roberts-Buchannan, Social Worker, Cabell County

Dr. Victoria Shuman, Physician, Greenbrier County