

**Traumatic Head and Spinal Cord Injury (THSCI) Trust Fund
ADVISORY BOARD MINUTES
November 12, 2020**

CALL TO ORDER

Andrew Kuyoro, the Chair of the Board, called to order the regular meeting of the Traumatic Head and Spinal Cord Injury Trust Fund Advisory Board at 10:10 a.m. on November 12, 2020. The meeting was held via zoom.

IN ATTENDANCE

Board Members: Andrew Kuyoro, Sherlyn Sullivan, Kenneth Alexander, Beth Arredondo, Gary Matherne, Melissa Bayham, and Michael Chafetz,

Board Members Not in Attendance: John Fanning, Representative Lawrence A. "Larry" Bagley, Thomas Loupe, Stephanie Fletcher and Hazel Odom

Agency Staff: Lora Bennett, Tonia Gedward, Florida Franklin, Ayanna Wilson, and John Korduner,

Contractors: Kimberly Hill

Public: None

BOARD MEETING ATTENDEES INTRODUCTIONS

Board Members and others in attendance introduced themselves.

APPROVAL OF MINUTES

The board reviewed the minutes from the last meeting held on February 13, 2020. Andrew asked if anyone had any comments about the minutes. The meeting minutes were approved as presented.

BUDGET/FINANCIAL REPORT – SHERLYN SULLIVAN

Sherlyn stated she has presented legislation, which was suggested by Rep. Bagley and Senator Claitor, at the last board meeting to protect the Trust Fund resources that is funded with statutorily dedicated funds. She said we need some authors to start the process. She stated Senator Claitor is no longer in the Senate. There's a huge influx of new Senators and Legislators this year about half of them were replaced. As she explained, there has been several incidents where the funds have been cut. She stated this has become a bigger problem for two reasons. The first reason is because they have taken all of the Trust Fund's state general funds during budget cuts in 2021. If they continue to reduce the Trust Fund, we may not have enough funding to serve the program participants. The second reason is COVID. She stated a lot of fees that help

fund the program were not being collected, especially in the earlier months. It's just starting to get back to normal but it's a slow process. Because of this, we are hesitant to open new cases. She stated that we were attempting to open all of the cases on the current waitlist but this has been put on hold because of COVID and funding. Sherlyn stated that changing the language would help alleviate some of the concerns. Ms. Arredondo asked if the committee members should reach out to their representatives and present something to them. Sherlyn stated we have to get an original author first. Once we get the original author, then that author will reach out to people he knows and we'll ask the committee to reach out to people they know to co-author. Mr. Kuyoro asked to keep us posted.

Sherlyn asked everyone to review the financial report. She stated as of right now we are okay. We have enough money from last year's carryover to go with what we are hoping to collect this year. She said we will be fine this year but she is not sure what will happen going forward, which is why we need to protect these funds. She stated everything on the financial report is status quo, but if anyone had any questions to let her know. Dr. Chafetz asked how the deposits were compared to past years. Sherlyn stated the deposits were down. She stated we are seeing \$25,000 per month less than we were seeing before COVID.

PROGRAM STATUS – TONIA GEDWARD

Current Eligible Participants

Currently, the Trust Fund is serving 621 participants. Between 2/14/20 and 11/12/20, the program closed 42 cases that were previously eligible.

Closed Cases between 2/14/20 and 11/12/20

<u>Closure Reason</u>	<u>Amount</u>
Closed Funds Expended	9
Death	19
Decline Services	1
Failure to Cooperate	1
Moved Out of State	3
Unable to Locate/Contact	9

Waitlist Applicants Update

As of 11/12/20, there are 231 applicants on the waitlist. We are not reviewing any applicants for eligibility to receive services at this time.

Program Highlights

Approximately 35 percent of the participant's eligible for the program are also eligible for Medicaid waiver services. As the program continued to look for ways to improve the program's internal processes, I found that there was a lack of communication between the program and the waiver support coordination agencies. The support coordinators did not know much about the program or how to help their participant's access services through the program. Often times I had to walk them through the process of completing forms while, giving them an overview of the program. This became very time consuming,

considering the fact that my knowledge of waiver services were limited. The program needed someone with specialized knowledge in waiver services.

As a result, in March, the program hired Florida Franklin as the Waiver Caseload Subject Matter Expert (SME). In this position, Florida provides support and training to the waiver support coordinators as needed; reviews all waiver participants' Participant Service Plans to ensure there are no duplication of services; and request annual documentation from waiver support coordinators for all waiver participants. In addition, she informs participants and their support coordinators of other services that may benefit them. She's even suggested other programs to non-waiver participants who are eligible for the Trust Fund program. Lastly, she serves as the liaison between the Trust Fund Program Manager and BIALA. She works with Kim to create innovative ways to bring program awareness to the public. She has become a true asset to this program.

Effective May 6, 2020, the program stopped reimbursing participants for paying Personal Care Attendants for care services. The payments are now being sent directly to the PCA provider or employee. The payments are being reported to the IRS as earned income.

We continue to update forms and policy to align with the program rules, guidelines and procedures. As we update policy and procedures, we also update the participant's Agreement of Understanding (AOU) form. This form explains the participant's rights and responsibilities and requires the participant's signature, acknowledging that they read and understood what they read. We require all program participants to sign the form at entry of the program and every year thereafter.

At the start of the pandemic, several of the municipalities were not submitting payments as required by law. In September, the program sent over 80 letters to non-payers. Since then, the program has seen a slight increase in payments.

As always, we continue to improve of our internal processes. We have decreased the processing time for payment from 2-3 weeks to 2-3 days.

BIALA – KIMBERLY HILL

Despite the continued challenging times, our mission has not waived, and our resource center (via phone and online) has remained open and active. We are happy to share that we provided and continue to provide many pertinent resources to individuals with brain and/or spinal injuries, caregivers, and professionals around the state.

Our helpline has remained consistent receiving on average 27 calls per months. Our website continues to receive good traction with an average of 1,000-page views per month. The resource guide has been updated and additional resources are constantly being added. Outreach continues around the state via phone calls, emails, Zoom calls, social media, newsletter, website, and email blasts. While hospitals are still not allowing in-services, I have continued sharing information about the trust fund program and application with case managers and therapy directors around the state.

Through our partnership with United Spinal Association, to date we have provided 300 N95 masks to brain and spinal cord injury individuals around the state. We were also given 50 Ready to Roll emergency preparedness backpacks where we specific information to Louisiana and areas of the state we added. These backpacks contain resources to educate individuals about being prepared, including check lists, evacuation plan/routes, and also tangible items useful during an emergency.

With the \$5000 grant that United Spinal Association awarded us in May, we have continued to provide healthy and prepared meals to families with loved ones with brain and spinal cord injuries. Along with giving the caregiver respite from cooking, these delivered meals have allowed the caregiver to remain at home, decreasing the chance that anyone in their home could become infected by COVID-19. It has also provided financial relief by providing cooked meals at no expense. Since the hurricanes affected the western part of the state, we have focused on getting meals to caregivers in the hurricane impacted areas.

Our virtual support group meetings for individuals with spinal cord injuries and brain injuries have continued where we have provided guest speakers on our Zoom calls. In July, Tonia Gedward and Florida Franklin were our guest speakers and provided information on the TH/SCI Trust Fund program. Some other topics have included: dealing with depression, ways to stay active during quarantine, assistive technology, technology tips, keeping your brain active, care of wheelchairs and working with insurance companies for wheelchair needs and more. Case managers and caregivers have also been participating on calls.

Through continuing our programs and services, we were awarded the 2020 Excellence in Programs and Services by the Brain Injury Association of America (BIAA) in October. We participated in both chapter leadership conferences throughout the month of October with BIAA and United Spinal where we gleaned great new resources to help those we serve. With Kimberly Hill being appointed as Chapter Liaison on the Board of Directors for United Spinal Association, we have been given priority when it comes to asking for assistance with resources on a national level.

To continue our programs and services, our fundraising efforts have not waived. In September, we were given a matching gift opportunity through the Oscar J. Tolmas Charitable Trust. As of November 9th, we reached our goal and will be gifted \$10,000. The most important financial resource we receive is through our contract with this program, and we continue to be grateful for this opportunity.

Over the summer, to bring some smiles and happiness to individuals with disabilities, we sponsored two adaptive water-skiing clinics in Bush. The clinics are operated by a non-profit organization called Ski Dawgs. If you would like to view a short video we made after one of the clinics, here is the link to YouTube: <https://youtu.be/GfekB7thUok>

Our Unmasking Brain Injury art exhibit is on the move again and is beginning to book up for 2021.

While challenges are still being presented, we look at them as opportunities. As 2021 quickly approaches, plans are being made on new ways to provide resources and support to those we serve. We will continue our mission to be the statewide resource for people impacted by brain and/or spinal cord injury.

OTHER BUSINESS

None

PUBLIC COMMENT

None

FUTURE MEETINGS

The next board meeting is scheduled for February 11th at 10:00 a.m., normally held at PACE, 7436 Bishop Ott Dr., Baton Rouge, LA 70806. However, due to the pandemic, the location will be determined before the February 1st.

2021 THSCI Advisory Board Meetings:

Thursday, May 13, 2021

Thursday, August 12, 2021

Thursday, November 4, 2021

ADJOURNMENT

With no further business to discuss, the meeting was adjourned at 11:00 a.m.