



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
Margaret M. O'Neill Bldg., Third Floor, Suite 1
410 Federal Street
Dover, Delaware 19901
302-739-3621

The Honorable John Carney
Governor

John McNeal
SCPD Director

BRAIN INJURY COMMITTEE DRAFT MINUTES
October 1, 2018 – 2:00 PM
Smyrna Rest Area Conference Room, Smyrna, DE

QUORUM PRESENT: 16

PRESENT: Ann **Phillips**, Chair, Parent of a survivor; Sharon **Lyons**, BIAD, Co-Chair; Christine **Applegate**, Bayhealth Neurosurgery; Sybil **Baker**, GACEC (obo Wendy Strauss); Andrew **Burdan**, Brain Injury Advocate/Support Group; Tammy **Clifton**, DOL/DVR, Senior Counselor (for Andrea Guest, Director); George **DeFarno**, Survivor and Director, Post-Acute Medical Center (Dover); Brian **Eng**, Esquire, Community Legal Aid Society, Inc., Disabilities Law Program (obo Laura Waterland); Katie **Freeman**, DSCYF, DPBHS, Psychologist (for Robert Dunleavy LCSW); Kristin **Harvey**, DDC (obo Steve Yeatman); Dale **Matusevich**, DOE, ECE, Education Associate, Transition Services (for Mary Ann Mieczkowski); Karen **McGloughlin**, Director of Women's Health (for Dr. Karyl Rattay, Director); Dorothy **Prior**, Psychologist (obo Marie Nonnemacher); Nancy **Ranalli**, Easterseals, Director of Community Outreach; Dr. Ron **Sarg**, DCVA/MOAA; DLP; Jamila **Waigwa**, DHSS/DSAAPD; and Dee **Rivard**, SCPD (obo John McNeal).

ABSENT: Linda **Brittingham**, Christiana Care Health System (CCHS); Thomas **Cairo**, Bayhealth Neurosurgery; Susan **Cowdery**, BCBS, Highmark Health Options; Debbie **Dunlap**, Parent of a survivor/Advocate; Mary **Iampietro**, A. I. DuPont Children's Hospital; Dr. Charles **Jin**, (DSAMH); (obo Elizabeth Romero, Director); John **McNeal**, Survivor/SCPD Director;;

GUESTS (Not able to vote or count toward quorum)

IN-PERSON – Lauren Brooking and Jessica Nolden, University of Delaware; Laura Howard, Deputy Director DHSS/DSAAPD; Jennifer Romano Morris

TELECONFERENCE PARTICIPANTS: Michelle Hood, St. Francis LIFE;

CALL TO ORDER

Sharon Lyons called the meeting to order at 3:15 p.m.

ADDITIONS/DELETIONS TO THE AGENDA

Sharon inquired if there were any additions or deletions for the agenda.

- Hearing none she proceeded to approval of past minutes.

APPROVAL OF PREVIOUS MEETING'S MINUTES

Sharon inquired if everyone had sufficient time to review the minutes of our last meeting from June 4. After receiving affirmative responses she called for discussion. A

- Christine Applegate requested a correction to the spelling of her name in the minutes from Christiana to Christine.
- Sybil Baker requested that her name be corrected to properly reflect her new last name changing Brown to Baker.
- Katie Freeman requested removal of a sentence relating to her providing intern contact information from the minutes.

Dr. Ron Sarg made a motion to approve the minutes as corrected; Brian Eng seconded the motion with voting committee members in attendance unanimously approving the motion to approve the minutes of the last meeting as corrected.

OLD BUSINESS

- **Membership Review**
 - VETERAN'S AFFAIRS HOSPITAL – Col. Ron Sarg will reach out to Francis Haggerty to explain that in-person attendance is required by Delaware's FOIA law found under Title 29, Chapter 100, §10004 in order to remain a voting member.
 - CHRISTIANA CARE HEALTH SYSTEM – Sharon Lyons sent an email to Linda Brittingham explaining the membership requirement for in-person attendance. Sharon requested official designation of someone who is able to attend meetings in-person.
 - SAINT FRANCES LIFE – Sharon spoke with Michelle Hood to inform her again about Delaware's in-person attendance requirement.
 - CHILD DEVELOPMENT WATCH PROGRAM – Ann contacted and they are willing to designate someone to attend the BIC meetings in-person. Ann requested that Dee send Sue Campbell the meeting dates, times, and meeting places so they can share the information with their designee.
 - HEALTHSOUTH REHABILITATION – Sharon will reach out once again to Mathew Gooch to ensure that his new Director of Therapy Megan Witman attends future meetings.
 - DEPARTMENT OF INSURANCE – Col. Ron Sarg reached out to Frank Pyle from the Department of Insurance who contacted him to let him know of his interest in serving on both the Brain Injury Committee and the TBI Application Review Committee.

- **Public Health TBI Data Availability**

- Ann told Karen McGloughlin the type of data that BIC is looking to receive from DPH and instructed Dee to send Karen a copy of the data received when DPH previously attended meetings.
- Karen inquired about any protocol for keeping track of concussions. Ann responded that before children return to sports activities they have to provide a physician's note. Unfortunately, there is no other tracking of concussion injuries.
- Karen provided Ann with a copy of the Division of Public Health's Data Information and Request Process that contained a link to the form the committee would need to complete in order to receive information.
- Karen also shared information on the Delaware Coalition for Injury Prevention suggesting that a member from their coalition would be of great assistance to this committee in obtaining information from the Delaware Trauma Systems Registry.
- Karen provided several pages of how information from the Delaware Trauma System Registry that included Type I, 2, and 3 Traumatic Brain Injury statistics. Dee will send a copy of this material to voting members along with the minutes of this meeting.

- **FOIA & DOJ**

- Ann shared information with committee members about Delaware FOIA and DOJ oversight of how meetings should be run properly. Our September meeting was cancelled due to lack of quorum for the meeting. Dee is begging everyone to respond to meeting requests as to whether or not they are attending to avoid meetings lacking quorum. Several Councils' are working with Legislators to try to get this changed; unfortunately, we are not sure how long it will take to obtain this change legislatively.

- **DHIN**

- Tom Cairo provided members an update of where he is right now due to only receiving one email providing some of the diagnosis codes that BIC wants to include in our DHIN information request.
- Tom needs the contact information of the DHIN individuals who attended one of our meetings. Dee will send Tom an email with the DHIN contact information.
- Tom announced that he cannot lead this subcommittee. It was his understanding that they were going to be a subset of the BIC.
- Unfortunately, Google Groups is not an option because of DTI data security requirements.
- Tom is happy to help people move this important issue forward; however, he needs an idea of who is going to lead it.
- The goal for this subcommittee is to understand as a state the number of persons with brain injuries whether they are traumatic or acquired brain injuries so we can begin to target money for these individuals.
- What are we as a committee trying to do for this population of people within the state?

- Karen McGloughlin volunteered to work on the DHIN Data Development Subcommittee.
- Ron Sarg shared that Governor Carper signed SB No. 230 into law relating to mental health drug addiction. This law requires providers to report specific information to DHIN. Unfortunately, there is no requirement to report information when an individual incurs a brain injury. The VA of Wilmington does not treat their brain injury patients in the State of Delaware. They send them to Virginia.
- Susan Cowdery suggested that perhaps the committee should consider building-in provider information for the TBI registry to assist in collecting clinical information and to help identify any need for provider re-education (i.e., reporting, resources, etc.)
- Ann reminded members of a previous discussion relating to prevention education being something this committee needs to address. Karen McGloughlin inquired if this committee has any funding? Ann responded that we did not. Karen suggested that perhaps students could drive this initiative.
- Katie Freeman is willing to join the DHIN Data Development Subcommittee; however, she does not want to lead it. She mentioned a CDC paper that was recently released with guidelines for pediatric brain injuries.
- Tom Cairo suggested picking a few items that we are interested in to start targeting resources for these items.
- Ann advised that this is the reason the committee reviewed membership in order to obtain active participants. She doesn't know if it is too soon or if we are too small to set up several subcommittees. Instead, she suggested starting with one issue and one committee. The TBI Application Review Committee is already in existence. Committee members need to decide on the next committee to form so we can move forward and stop just talking about it monthly.
- Are we looking at a preventative outreach project? Yes.
- If every hospital is not part of the DHIN, and reporting is voluntary, we will miss some of the information and parts of the population. We may be missing concussion/TBI for people with traditional insurance who see their Doctor. However, the DHIN is a great place to start to obtain some of the more serious injuries even though we may miss some of the mild to moderate injuries due to some people going to the hospital only to be told that they do not have a brain injury because they did not have a brain bleed.
- When someone is diagnosed with concussion they do not get Medicaid LTC.
- Not all insurance payers report to the DHIN. Nothing is completely regulated. However, they are starting to put laws in place to make reporting a requirement instead of an option.
- The level of detail submitted to DHIN for reportable injuries is not obligated like it is for childhood vaccinations. Still, a lot of ED visits are being reported. EPIC has a DHIN interface which means that Bayhealth can see information from DHIN and DHIN obtains information from Bayhealth records. Bayhealth is working to try to get to more of a universal health record.

- An educational piece for physicians on information that is important for this committee to receive, hopefully in timely manner is necessary.
- Delaware needs a TBI Registry which we cannot get without receiving the necessary information. There are existing registries but they all collect different information.
- Registries are great and while the Bayhealth stroke registry is uniform, it is unfortunately an input only registry. A Brain Injury Registry is a primary need in order to obtain important data.
- We need a Brain Injury Registry in order to be able to apply for federal grants and funding. The HRSA Brain Injury Grants require states to have an existing Brain Injury Registry and unfortunately, we do not have the demographics.
- Brian Eng summarized that this committee has two very different problems. One is trying to gather the necessary data and the second is trying to get people to check the right box when they patients come-in for treatment. He suggested starting a small pilot program to encourage physicians to enter the correct data. Once we know that we have data that we can rely on, and once there is a system that is working for one hospital, we would have something to replicate by starting small and moving it around.
- Who would we start it with? What would we do about inconsistencies? What is the VA doing with their brain injuries? (They send them out of state.) What is the VA doing with their brain injury information? Would we need legislation? (Yes, unless it becomes part of an existing system.)
- We can look at what have other states done; although Nancy advised that we have done that. She thinks it is great to look into what information we can obtain from the DHIN along with what information we need hospitals to enter into the DHIN.
- Ann feels that the committee should first educate hospitals on specific information we need collected. Karen shared that it takes 6 months to 1 year to add anything new to DHIN. The committee first needs to submit a request so it can go through case review. We need to look into how we change the process.
- Tammy Clifton understands why we have to look at it from a medical standpoint. Dale was able to pull up some figures and Tammy has other information that she can provide. The Brain Injury Registry would be separate from the DHIN. We need to start our Delaware Brain Injury Registry by looking at how the Bayhealth Stroke Registry started.
- Susan reported that some of the groundwork has already been done by the VA. The CDC breaks it down a little differently. She recommended reviewing how they collect and report their information.
- DVR makes their decisions based on the information provided by Doctors. While there is going to be some overlap, such as the DVR system possibly containing all 77 of Dale's people, isn't something better than nothing. Tammy agreed with starting on other educational programs.

- Karen advocated against including DOE information to information already gleaned from DVR medical information since it will incur duplication. We can look at all of these individually and pull something together.
- Nancy made a motion for Karen to be the DHIN subcommittee chair. Tom advised that he is willing to support but he cannot run it alone.
- Ann advised that first we need a motion to form the DHIN Data Subcommittee.
- Sharon made a motion to form the Data Development Subcommittee that Tom seconded with voting members in attendance unanimously approving the motion.
- Tom volunteered to co-chair the BIC Data Development Subcommittee (BIC_DDS) with Karen McGloughlin. Ann Phillips volunteered to assist with research and Susan Cowdery and Katie Freeman both volunteered to join the committee. Tom agreed that a small subcommittee is better.

BIC_DDSC Members

- BIC_DDC subcommittee members are Karen McGloughlin, Tom Cairo, Susan Cowdery, Ann Phillips and Katie Freeman.

BIC_DDSC Next Steps

- Karen and Tom agreed to reach out to Linda Brittingham and Michelle Hood for information or a contact at their locations for information.
- When applying for a grant ensued we will need a lead agency and someone from that agency designated for the Registry.
- There are graduate students at the U of D that can help apply for grants. Karen advised that Mary Sue Jones retired. She was very helpful with obtaining the information that we previously received for the Brain Injury Assessment.
- Karen felt that a collaboration between BIC and the Injury and Prevention Coalition would be helpful and should be our next order of business.
- Dee will email contact information for the new subcommittee members to Karen McGloughlin and Tom Cairo.
- Ann Phillips shared that previously there was a presentation done with students that it would be nice if they could present it to the committee for consideration as an educational outreach.
- Sharon suggested videotaping one of the sessions from the Brain Injury Conference to use for educational purposes.
- The DDS will include potential questions BIC may want to ask.

• BIC Subcommittee Updates

- Nancy reminded members that there is money available for persons with traumatic brain injuries and requested them to share the note from the SCPD Facebook page to their organization's Facebook pages.

NEW BUSINESS

- Prevention and Outreach Subcommittee — Nancy suggested not forming another subcommittee for at least a month or two when we have more members participating so different subcommittees can have different members volunteering. The committee agreed to revisit this in January; although we can still determine the

types of things that we want the subcommittee to handle by adding it to the agenda each month.

ANNOUNCEMENTS

- Katie advised that Sharon is going out to high schools to provide education on concussions. Could someone go to talk to different groups about brain injuries? Sharon is presenting to practical nursing students next week at a training school.
- Col. Ron Sarg attended a conference two-weeks ago that provided excellent information. DelTech will have a bachelor's degree graduation in December for their School of Nursing and Wesley also has a school of nursing.
- Bayhealth prepares a newsletter that is sent to patient's homes. Tom Cairo will reach out to some of the patients to see if they would be willing to participate.
- BIAD also has a newsletter that Sharon will ask to share the information in their next issue.
- The Commission of Veteran's Affairs also has a newsletter. Ron Sarg added that Sable Vance is the point of contact.
- Susanna stated that the TBI Fund application intimidates clients and should be written at a 6 grade level.
- The Brain Injury Conference is on Friday, March 8 at Dover Downs. Sharon added that someone is speaking on diversity and behaviors after a brain injury. She asked members if they should include a session on domestic violence since impulse control is an issue for individuals with brain injuries. Jim Mills will do an adult concussion panel and an A. I. DuPont Hospital therapist will do a pediatric panel. Please provide Sharon with any ideas that would be good to add to the conference.
- Susan suggested reaching out to local athletic coaches to encourage their participation in some of our initiatives because of sports related concussions; however, Ann shared that there is already training included under the concussion legislation.
- Tom Cairo shared that one piece of very positive feedback he received from the team is OT, SLT, PT and their ability to do alternative therapy at home without needing specialized tools. He will see if someone from one of his therapy departments is interested in doing a presentation. Christine Applegate and Donna Dixon are helping Sharon.
- Karen asked if Sharon included anything from Trauma Matters relating to the ACE Study (thousands of youth were asked a list of 10 questions). Based on the number of positive response they assigned the youth a rating number. Those higher than a rating of 4 were considered have experienced trauma. It is also important to consider how behaviors change later in life. Trying to make Delaware a trauma informed state by trying to understand that what happened to them up to that particular point is affecting their behaviors now. Leslie Brower is the key person behind this movement. Dee will share Karen's email address with Sharon. Parents and caregivers could better understand why the patients they are caring for act the way they act.

- Cognitive Rehabilitation Therapy is covered by health plans and focuses on behaviors and memory issues as well as attempting to regain some skills.
- Ann Phillips is speaking about what happens next!
- Karen asked if there is a way to get him in touch with the YMCA, Easterseals and Camp Fairlee since there is an age demographic that is unaddressed. There is an opportunity to get adults currently in day programs to attend perhaps from DovePoint in Salisbury or other day programs and facilities.
- Karen advocated the need for a communications program to spread the word about available programs in Delaware by having 3 or 4 people put together information at a sixth grade reading level to communicate once a quarter. However, that is the purpose of the caregiver resource centers statewide. Ann shared that Family Voices does a weekly Facebook live session shares general information and disability specific information. They talk about any kind of information that people want to hear about.
- Nancy Ranalli shared that Respite funding is available from Easterseals and encouraged people to fill out applications.
- Brian Eng made a motion to adjourn that Sharon Lyons seconded. Ann called for discussion with Col. Ron Sarg wanting to provide additional information to members about his agency's open website that allows other agencies to post information to once they are registered with Delaware Joining Forces (DJF). Users can access the DJF server provider directory on www.delaware.gov/djf to search the directory from the home page by service type and county location. Agencies provide a link back to the information on their individual websites. Delaware Joining Forces network is a community-level effort that directly supports military service members, veterans and their families (SMVF) in the areas of: behavioral health, education, employment, faith, financial homelessness, housing, legal, military youth, and wellness. Service providers can register at www.delaware.gov/djf by clicking register from the home page to obtain a login and password and then selecting "start an application."
- Once finished, Col. Ron Sarg made a motion to adjourn; however, since there was already a motion on the floor to adjourn from Brian Eng that was seconded by Sharon, Ann called for a vote by committee members present who unanimously approved the original motion to adjourn.

ADJOURNMENT

- With no further business to discuss the meeting adjourned at 3:45 p.m.

NEXT MEETING

The next Brain Injury Committee meeting is scheduled for
Monday, November 5 at 2:00 p.m., in the
 Appoquinimink State Service Center Conference Room