

Task Force on Best Practices and Licensing of Non-Transplant Organ Donation Organizations

Tuesday, August 24, 2021
10:00 a.m. – 12:00 p.m.

Michael A. Bilandic Building
160 North LaSalle Street, 6th Floor, C-600
Chicago, IL 60601

Meeting Minutes

1. Welcome by Secretary White, roll call and brief introductions

Secretary of State, Jesse White, called the meeting to order at 10:05 a.m. He thanked everyone for attending the first meeting of the Non-Transplant Organ Donor Task Force and asked Micah Miller to take the roll call.

Mr. Miller reminded members to wear their face mask, maintain social distancing and to observe all safety protocols. He then asked for members to briefly introduce themselves during roll call. The following were present:

Task Force Members	Present	Absent
Jesse White, Secretary of State (Chairperson)	X	
Amy Williams, Legal Counsel, Secretary of State's Office (Chairperson)	X*	
Connie Boatman, Director, SOS Organ/Tissue Donor Program	X	
Chaundra Bishop, Champaign Public Health District	X	
Dan Brady, Representative, 105 th District	X	
Patricia Van Pelt-Scott, Senator, 5 th District	X	
Aaron Beswick, Senior Policy Advisor, IL Dept. of Public Health	X	
Jil Tracy, Senator, 47 th District	X**	
Callum Ross, Ph.D., University of Chicago	X	

*Amy Williams was appointed to serve as Chairperson for Secretary White midway through the meeting.

** Matt Pickett, Legislative Assistant for Senator Tracy, attended on her behalf.

Administrative Staff	Present	Absent
Micah Miller, Program Staff, Secretary of State's Office	X	
Dave Fuchs, Program Staff, Secretary of State's Office	X	
Tiffani Baum, Information Technology, Secretary of State's Office	X	
Brian Hollis, Information Technology, Secretary of State's Office	X	

Secretary White recognized that a quorum was present (5 or more). The following individuals were also in attendance:

Gary Giacomelli, Carle-Illinois College of Medicine
Bill O'Connor, Anatomical Gift Association of Illinois
John Butsch, BRCIL Victim
Dawn DiNardo, BRCIL Victim
Dave Druker, Press Secretary, Secretary of State
Irene Lyons, General Counsel, Secretary of State
Nekya Hall, House Liaison, Secretary of State
Nathan Mansfield, House Republican Staff

Introductions:

Ms. Boatman said that she represents the Secretary of State's office regarding organ and tissue donation and also serves in a capacity that maintains public trust on this important issue.

Ms. Bishop noted that she resides in Urbana, Illinois where she works in the public health sector for the Champaign Public Health District.

Representative Brady noted that he served as McLean County Coroner prior to his service to the 105th legislative district, which largely encompasses the Bloomington/Normal area. He indicated that he met several of the affected family members in July 2019 and worked with the Secretary of State's office to produce Senate Bill 363, which created the task force. He indicated his desire to bring a resolution to this issue.

Mr. Beswick said that he is Senior Policy Advisor at the Illinois Department of Public Health and has experience with the donation issues in the public health realm including the recent work on practitioner orders for life-sustaining treatment.

Dr. Ross said that represents the University of Chicago where he has taught anatomy for the past 25 years and has directed the program for the past 15 years. He noted his work with the Board of Directors for the Anatomical Gift Association of Illinois, where he has served as President for the past 10 years.

Senator Van Pelt-Scott noted that she was a co-sponsor for Senate Bill 363, indicated her desire to bring solution to this issue and thanked Secretary White for bringing this forward.

Mr. Pickett, on behalf of Senator Tracy, recognized the severity of this issue, thanked Leader McConchie for the appointment to the task force and thanked everyone for their dedication to bringing about a meaningful resolution.

2. Remarks by Secretary White

Secretary White thanked the members for their participation and victims for their willingness to share testimony as they look for answers on the issue of body donation. He noted that this task force was created by the Illinois General Assembly and includes representation by all four legislative caucuses. He also noted that Governor Pritzker is represented through his appointee and by the Illinois Department of Public Health.

Secretary White noted that a series of meetings will be held to consider input from families who were victimized, medical professionals, educators and transplant organizations with the goal of determining what can be done to improve the system and to issue those finding in a report to the General Assembly in January of 2022.

Secretary White said that Amy Williams, from his Legal Counsel's office, will serve as his designee and as Chairperson moving forward. He also noted that Ms. Boatman, who is the Director of his Organ/Tissue Donor Program, will serve as his other appointee to the task force. He thanked everyone for volunteering their time and energy to this cause and indicated the strong desire to bring forward a transparent and positive resolution to the body donation issue to present to the General Assembly and the people of Illinois.

3. Family testimony

Ms. Williams thanked Secretary White for his remarks and asked the members to prepare for testimony from family members who will be sharing their firsthand experiences.

John Butsch:

Mr. Butsch thanked Secretary White for the opportunity to share his story. He noted that Gift of Hope is a model organization on organ donation, but it is an incomplete project. There is no accountable, systematic, or educational protocol in Illinois for the donation of non-transplant body and tissue. He noted that when a registered donor's organs and/or tissue does not meet the certification protocol for human transplant, families are left scrambling to meet their loved ones' final wishes.

He said that he is the father of Alexandria Orba, who was a victim of Biological Resources Center of Illinois' (BRCIL) misdeeds. His daughter died in October 2014 and made it known that she wanted to be an organ donor, however, due to the circumstances of her passing she could not be a donor. Mr. Butsch knew of her intent to use her body to benefit anyone and consequently turned to BRCIL. After a preliminary meeting, the decision was made to donate her body to BRCIL.

Mr. Butsch showed the members a box, which contained Alexandria's cremated remains that were returned to him from BRCIL. He indicated that the remains have since been buried in a memorial for her, but he still keeps the box. He also displayed a certificate from BRCIL, verifying

that these were in fact her cremated remains. He said that this was a deception and should be criminal, because in early 2015, Mr. Butsch received a call from Special Agent Paul Johnson with the FBI's Detroit, Michigan office, concerning a raid that was conducted on BRCIL located in Rosemont, Illinois. Agent Johnson said that Alexandria was among those who were identified.

Mr. Butsch stated that his daughter has been in a storage freezer in Detroit along with 190 other families' loved ones, while federal prosecutors indicted Arthur Rathburn and eventually led to charges against Donald Greene Sr. and Donald Greene II of BRCIL. He noted the emotional toll over the 7-year period and that there has never been any investigation or prosecution into the events in Illinois (and likely may not occur due to the statute of limitations).

Mr. Butsch emphasized that non-transplant donations allow for the medical education, which is necessary for organ donation to succeed and stressed the need to have a system in place for non-transplant body and tissue donation to be better regulated. He asked for the Secretary of State's office to expand the understanding of what it means to sign up as an organ donor, because there are families like his who will not be able to honor their loved one's wishes, but may still qualify for medical research and education.

Ms. Boatman thanked Mr. Butsch for his testimony and indicated that they had both talked about these issues in 2019. Since then she noted in depth conversations regarding whole body donation had occurred with Dr. Ross and the Anatomical Gift Association. She indicated that in her role with the Organ/Tissue Donor Program, they make sure that the public is aware of the three different types of donation - 1) Cadaveric Donation, which is organ donation when a person is deceased, 2) Living Donation, which is organ donation between two living persons, and 3) Whole Body Donation, which occurs when someone decides to donate their body to science for the purpose of medical advancement.

Rep. Brady extended his sympathy to Mr. Butsch and said that there needs to be consideration of laws that are currently in the statutes, which can be better utilized for prosecution. He also recognized the need for awareness and education on this issue. He asked Mr. Butsch if there was a preliminary meeting with BRCIL before any decision was made and Mr. Butsch confirmed. Rep. Brady asked if BRCIL made arrangements to transfer his daughter from the medical examiner's office to their facility and Mr. Butsch confirmed and indicated that it required his signature to a contract.

Rep. Brady asked if anyone from BRCIL explained the extent of what would be possible with whole body donation. Mr. Butsch said that they did and the emphasis was very clear that Alexandria's body would be used for medical research, possibly medical training at Universities and that parts of her body may be used, which he had no issue with. Rep. Brady asked if there was a financial transaction involved with the donation. Mr. Butsch said no, and that he was surprised that there was no cost by BRCIL to do this. He noted a discussion with staff at BRCIL where it was explained to him that when a whole body is donated to a University, there is a fee that the University pays. He also noted that staff explained when a part of a body is used for similar purposes, there would be a fee applied again.

Rep. Brady asked if any information was shared on how to receive his daughters remains after the research was complete. Mr. Butsch said that it was made clear her body would be tested to determine if it could be used and if so, after the research is completed, her body would be cremated and returned to the family. He also said that he was surprised to receive a call in November 2014 from BRCIL telling him that her remains had been cremated and were ready to be picked up. He noted that the family believed that these were her full remains, yet they received a call from the FBI in early 2015, which stated otherwise.

Rep. Brady asked if there was an understanding that Alexandria's full body may not be returned. Mr. Butsch said no, and referred to a letter on file from BRCIL stating how Alexandria's remains were used and that those remains were all returned to BRCIL and included in the ashes that he had received. Mr. Butsch said that BRCIL should have told the truth in the documents they provided and explanation they gave.

Dawn DiNardo:

Ms. DiNardo thanked the members for allowing her to tell her story. She said that her father, Frank DiNardo, was a Veteran, under care at Edward Hines, Jr. VA Hospital where he found out that he was dying. He was informed that BRCIL would be option to consider where his body would be of great use and service to medical researchers. She said that her parents had time to consider this option and to meet with BRCIL to discuss how to proceed. They were informed that upon death, BRCIL would transport the body to their facility, find a use for organs and tissue within weeks, and, upon the completion of research, the remains would then be returned to the family.

Ms. DiNardo said that her father died in November 2011 (her mother died in 2013), they proceeded with whole body donation and noted that they did in fact receive the remains, which they believed were his full remains returned to them. On May 2, 2019, Ms. DiNardo received a phone call from the U.S. Department of Justice (USDOJ) explaining that her father was a victim of a crime and his head had been found in a warehouse in Michigan that the FBI raided in 2013. His head was taken to a Detroit FBI evidence facility and kept frozen during the indictment, conviction and sentencing of Arthur Rathburn, a body broker who owned the warehouse in Michigan. The USDOJ informed Ms. DiNardo that the trial was over, the evidence was being cremated and they wanted to know if she wanted the remains.

Until the phone call, Ms. DiNardo never knew about the trial or that her father's remains were sitting in a holding facility in another state. She said that BRCIL sold her father's head to Arthur Rathburn for \$500 in August of 2012. She said that her father's body was rented out numerous times for an untold amount of money. Between rentals, his body was kept in a filthy, unsanitary warehouse, full of flies where body parts from multiple donors were frozen together and separated often by use of a crowbar. She said that the use, degradation and profit is not what her father signed up for, rather they expected to be handled with care, dignity and purpose. She said that her family was lied to and robbed of the opportunity to make truly informed decisions. Ms. DiNardo said that there was no misunderstanding about use, because this affected too many families.

Ms. DiNardo said that true consent cannot be obtained through misrepresentation and because of the loss of oversight, her family has to continually relive this grief. She said that because her experience is so unbelievable, it puts a sense of shame on her family because people cannot believe that this was allowed to happen. She implored the members of the task force to work toward regulation and oversight of this industry.

Mr. Butsch thanked Ms. DiNardo for her testimony and wanted the members to know that BRCIL told families about a memorial in Elm Lawn Cemetery in Elmhurst, IL, which included the names of donors as a tribute to their contributions. He used to visit the memorial and saw it as a tribute to families, but now sees it in a negative light. He also wanted the members to know that 190 families were affected, and while some of those have received final remains of their loved ones, a majority are in the process of receiving cremated remains in the coming months.

Dr. Ross said that this is not the way body donation should proceed and he shares in the horror and grief of Ms. DiNardo and Mr. Butsch. He said that respect, integrity, professionalism honesty and transparency are all core values at the Anatomical Gift Association and acknowledged that they didn't receive any of that. He noted the value that whole body donation provides in education and that no organization should behave as BRCIL has.

Rep. Brady extended his sympathy to Ms. DiNardo and asked for clarification if someone had made a recommendation to use BRCIL. Ms. DiNardo said yes, when her father found out that his condition was terminal, he was referred to BRCIL and her father and mother arranged for a meeting. Rep. Brady asked if there was a financial transaction involved and Ms. DiNardo said no, it had been made clear that this was a donation and that their company operated by receiving funds from educational institutions.

Rep. Brady asked if Ms. DiNardo believed that her parents were told about the possibility of parts of the body being used and limb separation being involved. Ms. DiNardo did not believe that this was made clear to them. She also said that in the paperwork that was provided, the average person would have a hard time understanding the medical terms that were referenced throughout. She said that a decision of this magnitude should be very clear and easy to understand to the person who is agreeing.

Rep. Brady asked if Ms. DiNardo believed that the remains she received were those of her father's and in their entirety. She said yes and she had no reason to suspect any different until hearing from the authorities.

Ms. Boatman thanked Ms. DiNardo for her testimony. She asked Ms. DiNardo and Mr. Butsch if there was a more clear understanding of the ways that their loved ones would be used in whole body donation, if it would have changed their decision. Ms. DiNardo said that her parents would have been opposed to the length of time their bodies would be used, the amount of transferring, the storage conditions and repeated profiting. Mr. Butsch said that he would have made the same decision, but families should be told the potential usages and given an option to say that they do not want to be used for crash testing, etc... He noted that a source of comfort when you lose a loved one is to know that their decisions are being honored.

Ms. Boatman recognized the need to advance medical science and is hopeful that the task force can come to a solution that brings comfort and transparency to families, while benefiting medical science and other industries for the common good.

Ms. Bishop thanked Ms. DiNardo and Mr. Butsch for their testimony and noted that no matter how uncomfortable the subject matter may be, the conversation needs to occur to bring about positive change.

Dr. Ross said that in his personal opinion, whole body donation organizations should be not for profit. He said there is a need for education so that people understand what whole body donation means, for them to know who are good organizations to donate to, and for them to have a good understanding of informed consent.

Carrie Burr:

Rep. Brady referred to a meeting in 2019 that Secretary White established to discuss this issue and noted testimony from Ms. Burr during that meeting. He read into the record a portion of her testimony, which was provided on June 26, 2019:

My name is Carrie Burr. My husband Russell died on March 29, 2012. We could not afford a funeral or a cremation. Someone put us in touch with Biological Resources (BRCIL) and we were told by them they would offer free cremation and my husband's body would be donated to science. Russ and I had always agreed on both of us being donors. Biological Resources seemed too good to be true and it was.

Rep. Brady noted that this was a common theme from family members who provided testimony and stressed the need for family members to have a full understanding of what they are agreeing to.

4. Housekeeping (OMA training, timeframe for business) – Micah Miller

Mr. Miller informed the task force that as members of a public body they are required to take Open Meetings Act training, which may be located at the Illinois Attorney General's website. He also noted that the task force is required to meet 5 times before the end of the year, which puts them on a very tight deadline. He thanked everyone for adjusting their schedules in order to make the first meeting possible and indicated that they will establish a date for their next meeting prior to adjournment.

5. Requirements of Public Act 102-0096 – Amy Williams

Chairperson Williams asked the members to reference Public Act 102-0096, which was signed into law on July 9, 2021. She noted that this was the work of Senate Bill 363, sponsored by Senator Van Pelt-Scott, Senator Hastings, Rep. Brady and Rep. Ammons. Chairperson Williams

said that the timeframe for business was necessary to bring about a positive change as urgently as possible, with the major requirement being the issuing of a report to the Governor and General Assembly before January 15, 2022. She noted that this report will be a collaborative process, speaking to national standards for best practices and will reference testimony from the families who spoke today.

6. Legislative history in Illinois and statutes in other states – Amy Williams

Chairman Williams indicated that prior to the next meeting, she will share with members state statutes and a federal statute in order to discuss considerations for Illinois. She noted that there would also be a discussion about what current laws in Illinois may be better utilized for these offenses.

7. Public comments

Mr. Butsch asked if there would be a way for the public to follow the progress of this task force. Mr. Miller indicated that agendas and minutes would be posted on the Secretary of State's website.

Senator Van Pelt-Scott thanked the families for sharing their testimony. She said that when legislators consider changes to laws, they need family experiences in order to produce the best results. She said that their stories will help bring positive change to the state of Illinois and possibly the entire country.

Rep. Brady thanked Secretary White and the families for the discussion that was started in 2019. He expressed optimism in working collaboratively to improve the system.

8. Set schedule of meetings

The members agreed to a tentative next meeting date of Tuesday, September 14, 2021. Mr. Miller said that he would coordinate a time and location for that meeting. Chairperson Williams noted the desire to have a Zoom link for each meeting moving forward, which would better allow participation. Mr. Miller said that he would try to secure the same meeting room again and Rep. Brady asked members to consider holding meetings in a downstate location.

9. Agenda discussion and adjournment

Chairman Williams said that the state and federal statutes will be a point of discussion for the next agenda. She thanked everyone for their participation and hearing no other comments, Ms. Williams made the motion to adjourn and Rep. Brady seconded. The meeting adjourned at 11:44 a.m.