



RON CHAPMAN, MD, MPH  
Director & State Health Officer

Vital Statistics Advisory Committee (VSAC)  
Vital Records Protection Advisory Committee (VRPAC)  
Joint Meeting  
Meeting Minutes for Wednesday, July 10, 2013  
9:00 AM



EDMUND G. BROWN JR.  
Governor

## ATTENDEES:

**Convener:** Krista Christian, MBA, Chief, Vital Statistics Unit

### Committee Members:

**Present:** Emily Putnam-Hornstein, PhD, Jonathan Teague, MCRP

**Phone:** None

### California Department of Public Health (CDPH) Staff:

**Present:** Tony Agurto, MPA, Terri Mack, MPH/HSA, Matt Conens, Cindy Tanaka-Fong

**Public Attendees:** Lexi Gill (MDRC), Sun Lee (Los Angeles County Public Health)

**Present:**

**CALL TO ORDER:** The meeting was called to order at 9:00 A.M.

## A/B. WELCOME/INTRODUCTIONS:

Research protocols are available for review on our Department's SharePoint site. Protocols are uploaded up to 3 weeks prior to the VSAC meeting and members were encouraged to download and review them early to avoid issues. The agenda and minutes are posted on the VSAC schedule website.

We currently have 7 committee members and we are still recruiting for committee members for VSAC/VRPAC. Interested parties can contact Krista Christian at (916) 552-9873 or [krista.christian@cdph.ca.gov](mailto:krista.christian@cdph.ca.gov).

## C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Emily Putnam-Hornstein motioned to approve the May 8, 2013 meeting minutes. Jonathan Teague seconded the motion. All Committee members voted to approve the minutes. There were no oppositions.

## D. VSAC RECOMMENDATIONS FROM THE PREVIOUS MEETING:

Attachment 1, the State Registrar's Response to VSAC Recommendations, is a recap of recommendations from the last meeting.

There was one project that was revisited from the March meeting, in which the committee recommended approval. Eight projects were reviewed with the recommendation of approval. Two projects

received approval with stipulation that new projects using the same data sets be presented to the Committee prior to commencement. The State Registrar adopted all recommendations.

#### **E. NEW BUSINESS:**

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The following project was reviewed at the July 10th VSAC meeting and the committee members sought additional information before recommending approval of the protocol.

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The first project reviewed by the Committee was:

**Project Title:** "Cancer Genetics Research Information System (CGRIS)"

**Principal Investigator(s):** Hoda Anton-Culver, PhD., Genetic Epidemiology Research Institute, Department of Epidemiology, University of California, Irvine

**Project Type:** New Project

**CPHS Approval:** Approved

**Project No.:** 12-06-0379

**Expiration:** April 4, 2014

**File(s) Requested:** 1970-2011 Death Statistical Master File (select variables)

**Requested Identifiers:** 1970-2011 Death Statistical Master File (Name, Certificate Number, SSN, Address)

**Personal Contact:** No

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** The Committee mentioned that SSN was not checked on the application but appeared on the list of data elements requested. Krista said we can clarify with the requestor but pointed out that there was nothing to prevent them from receiving that information.

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** Committee members voted in favor of recommending approval of the data request. There were no oppositions.

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The second project reviewed by the Committee was:

**Project Title:** "Locomotion and Psychological Development in Infancy"

**Principal Investigator(s):** Joseph Campos, PhD, University of California, Berkeley

**Project Type:** New Project

**CPHS Approval:** Requested

**Project No.:** Pending CPHS approval

**Expiration:** Pending CPHS approval

**File(s) Requested:** 2012-2013 Birth Records (selected variables), 2000-2009 Birth Cohort File (selected variables)

**Requested Identifiers:** Address

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** Originally, the request was for the 2012 Birth Cohort File but since that was not available, the request was revised to reflect 2012 Birth Records. The Committee commented that most requests for projects involving direct contact with families had the provision to use death records to rule out contacting families with decedent child. Terri suggested that we could offer the cross match file we do for NCHS with federal data submission. The cross match file includes infants that have died crossed with existing birth certificates. Discussion included the invoice as this is considered a custom data set as we do not have current data.

**VSAC Recommendation(s):** The committee recommended approval of the four University of California, Berkeley protocols with stipulation that the researcher use some sort of death data or some sort of data to ensure that grieving parents are not contacted as part of process of this study.

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**VSAC Motions:** Jonathan Teague motioned to recommend the approval of the data. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** The Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

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The third project reviewed by the Committee was:

**Project Title:** "Visual Proprioception and Wariness of Heights in Infants"

**Principal Investigator(s):** Joseph Campos, PhD, University of Berkeley

**Project Type:** New Project

**CPHS Approval:** Requested

**Project No:** Pending CPHS Approval

**Expiration:** Pending CPHS Approval

**File(s) Requested:** 2012-2013 Birth Records (select variables)  
2012-2013 Birth Records

**Requested Identifiers:** Address

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** Please refer to the first project for discussion as this applies to all projects that were submitted by Dr. Campos.

**VSAC Recommendation(s):** Approve the data request with stipulation that parents of deceased infants are not contacted.

**VSAC Motions:** Motion has been carried covers projects 2 through 5.

**VSAC Vote:** The Committee members voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

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The fourth project reviewed by the Committee was:

**Project Title:** "Emotional communication of Rules to Infants"

**Principal Investigator(s):** Joseph Campos, PhD, University of Berkeley

**Project Type:** New Project

**CPHS Approval:** Requested

**Project No.:** Pending CPHS Approval

**Expiration:** Pending CPHS Approval

**File(s) Requested:** 2012-2013 Birth Records

**Requested Identifiers:** Address

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** See discussion above.

**VSAC Recommendation(s):** Approve the data request.

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**VSAC Motions:** Please refer to the first project for discussion as this applies to all projects that were submitted by Dr. Campos.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The fifth project reviewed by the Committee was:

**Project Title:** "Investigating the link between walking & language development"

**Principal Investigator(s):** Joseph Campos, PhD, University of California, Berkeley

**Project Type:** New Project

**CPHS Approval:** Requested

**Project No.:** Pending CPHS Approval

**Expiration:** Pending CPHS Approval

**File(s) Requested:** 2012-2013 Birth Records

**Requested Identifiers:** Address

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project.

**VSAC Discussion:** Please refer to the first project for discussion as this applies to all projects that were submitted by Dr. Campos.

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Motion has been carried covers projects 2 through 5.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The sixth project reviewed by the Committee was:

**Project Title:** "The Path to Language and Literacy: A Cross-Linguistic Longitudinal Approach"

**Principal Investigator(s):** Margaret Friend, PhD, San Diego State University, Infant and Child Development Laboratory

**Project Type:** New Project

**CPHS Approval:** Approved

**Project No.:** 12-04-05

**Expiration:** April 5, 2013

**File(s) Requested:** Death Records between 6/1/11 and 7/1/12, Birth Records for Children between 6/1/11/ and 7/1/12

**Requested Identifiers:** Death Records (Descendant's DOD), Birth Records (Children's DOB)

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** No discussion

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Emily Putnam-Hornstein motioned to recommend the approval of the data. Jonathan Teague seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

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The seventh project reviewed by the Committee was:

**Project Title:** "The California Maternal Data Center: Establishing a Statewide Data Center for Use in Rapid-Cycle Maternity Care Improvement Projects"

**Principal Investigator(s):** Jeffrey B. Gould, MD, MPH & Elliott Main, MD, Division of Neonatal and Developmental Medicine, Stanford University

**Project Type:** Continuing Project

**CPHS Approval:** Requested

**Project No.:** Pending CPHS Approval

**Expiration:** Pending CPHS Approval

**File(s) Requested:** 2013-2014 Monthly Birth Records (select variables)

**Requested Identifiers:** No personal identifiers

**Personal Contact:** No

**Identifiers Released:** Yes

**History:** Previous Data Request

**VSAC Discussion:** No discussion

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The eighth project reviewed by the Committee was:

**Project Title:** "North American Wilms Tumor (NAWTS)"

**Principal Investigator(s):** Rayjean Hung, Samuel Lunenfeld Research Institute, Mount Sinai Hospital

**Project Type:** New Project

**CPHS Approval:** Requested

**Project No.:** Pending CPHS Approval

**Expiration:** Pending CPHS Approval

**File(s) Requested:** 1997-2015 Birth Statistical Master File (select variables)

**Requested Identifiers:** Name, Certificate Number, Address

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** This project had no provision from removing descendant's children. The Committee was concerned that they would be using the children's name in the mailing. The Committee recommended provisional approval with the use of death records before reaching out to the descendant's family.

**VSAC Recommendation(s):** The Committee has recommended approval with stipulation that death data be purchased to remove decedents from the cohort of study.

**VSAC Motions:** Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the request. There were no oppositions. Motion carried.

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The ninth project reviewed by the Committee was:

**Project Title:** "Mother and Infant Home Visiting Program Evaluation (MIHOPE)"

**Principal Investigator(s):** Virginia Knox, PhD, MDRC

**Project Type:** New Project

**CPHS Approval:** Approved

**Project No.:** 13-02-1114

**Expiration:** June 7, 2014

**File(s) Requested:** 2010-2016 Birth Statistical Master File, 2010-2016 Death Statistical Master File (select variables), and 2010-2016 Fetal Death Statistical Master File (select variables)

**Requested Identifiers:** BSMF (Name, Certificate Number, Address),  
DSMF (Name, Certificate Number, Social Security Number, Address)  
FDSMF (Name, Certificate Number)

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** Krista stated that only 2010 and 2011 files are available. The Committee noticed that they were requesting marital status and breast feeding and wanted to know if this was on the standard form. Discussion included the release of marital status. Krista provided Health and Safety Code 102426(b) which states notwithstanding any provisions of law to the contrary, information collected pursuant to subparagraph (A) of paragraph (2) of subdivision (a) shall not under any circumstances be disclosed or available to anyone except to the department for demographic and statistical analysis, and to the federal government, without any personal identifying information, for demographic and statistical analysis.

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Jonathan Teague motioned to recommend the approval of the data. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The tenth project reviewed by the Committee was:

**Project Title:** "Birth Certificate and Fetal Death Certificate Data Matching for the Post-Licensure Rapid Immunization Safety Monitoring (PRISM) Program"

**Principal Investigator(s):** Chunfu Liu, Healthcore Inc.

**Project Type:** New Project

**CPHS Approval:** Approved

**Project No.:** 13-04-1200

**Expiration:** June 6, 2014

**File(s) Requested:** 2011 Fetal Death Statistical Master File (select variables), 2004-2011 Birth Statistical Master File (select variables)

**Requested Identifiers:** FDSMF (Name, Certificate Number), BSMF (Name, Certificate Number, Address)

**Personal Contact:** No

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** No Discussion

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Emily Putnam-Hornstein motioned to recommend the approval of the data. Jonathan Teague seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The eleventh project reviewed by the Committee was:

**Project Title:** "Understanding the Relation between Sleep and Memory in Infants"

**Principal Investigator(s):** Angela Lukowski, PhD, University of California, Irvine

**Project Type:** New Project

**CPHS Approval:** Approved

**Project No.:** 12-10-0785

**Expiration:** January 3, 2014

**File(s) Requested:** 2012 Birth Statistical Master File (select variables), 2012 Infant Death File (select variables), 2012 Death Statistical Master File (select variables)

**Requested Identifiers:** BSMF (Name, Certificate Number, Address), Infant Death File (Name, Certificate Number), DSMF (Name, Certificate Number, SSN, MMN)

**Personal Contact:** Yes

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** No Discussion

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Jonathan Teague motioned to recommend the approval of the data. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The twelfth project reviewed by the Committee was:

**Project Title:** "Investigation of Racial/Ethnic Differences in Placental Weight and Birth Weight"

**Principal Investigator(s):** Latha Palaniappan, MD, MS, Palo Alto Medical Foundation Research Institute

**Project Type:** New Project

**CPHS Approval:** Requested

**Project No.:** Pending CPHS Approval

**Expiration:** Pending CPHS Approval

**File(s) Requested:** use of birth files they had purchased for another project.

**Requested Identifiers:** BSMF (Name, Address),

**Personal Contact:** No

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** No Discussion

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Emily Putnam-Hornstein motioned to recommend the approval of the data. Jonathan Teague seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

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The thirteenth project reviewed by the Committee was:

**Project Title:** "Firearm Deaths"

**Principal Investigator(s):** Michael Luo

**Project Type:** New Project

**CPHS Approval:** No

**Project No.:** No

**Expiration:** No

**File(s) Requested:** 1999-2011 Death Statistical Master File (select variables)

**Requested Identifiers:** Name, Address

**Personal Contact:** No

**Identifiers Released:** No

**History:** New Research Project

**VSAC Discussion:** Comments from the Committee included the following:

- Concern with the use of death data including personal identifiers
- Whether or not CPHS will approve a data request with a non-research purpose
- Whether or not the data should be released with personal identifiers
- Can a state file number be used to identify a record with the coroner
- Whether or not the requester should be required to modify the application.

**VSAC Recommendation(s):** Approve the data request with stipulation that no family members be contacted.

**VSAC Motions:** Emily Putnam-Hornstein motioned to recommend the approval of the data with stipulation that no family members be contacted. Jonathan Teague seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

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The fourteenth project reviewed by the Committee was:

**Project Title:** "Maternal Age-Specific Prevalence Rates of Chromosome Abnormalities by Race/Ethnicity in the Kaiser Health Plan in Northern and Southern California"

**Principal Investigator(s):** De Kun Li, PhD, Kaiser Permanente

**Project Type:** Continuing Project

**CPHS Approval:** Approved

**Project No.:** 12-06-0407

**Expiration:** August 2, 2013

**File(s) Requested:** 2011 Merged Death File (select variables)

**Requested Identifiers:** Name, Certificate Number

**Personal Contact:** No

**Identifiers Released:** No

**History:** Previous Data Request

**VSAC Discussion:** No Discussion

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Jonathan Teague motioned to recommend the approval of the data. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The fifteenth project reviewed by the Committee was:

**Project Title:** "Impact of Economic Factors on Health Outcomes at Birth"

**Principal Investigator(s):** Suzanne Bostwick, Los Angeles County of Public Health

**Project Type:** Continuing Project with changes to the protocol

**CPHS Approval:** Approved

**Project No.:** 12-08-0619

**Expiration:** January 31, 2014

**File(s) Requested:** 1997-2011 Birth Statistical Master File (select variables), 2005-2011 Death Statistical Master File (select variables)

**Requested Identifiers:** BSMF and DSMF (addresses obtained from Los Angeles County Department of Public Health)

**Personal Contact:** No

**Identifiers Released:** No

**History:** Previous data request

**VSAC Discussion:** No Discussion.

**VSAC Recommendation(s):** Approve the data request.

**VSAC Motions:** Emily Putnam-Hornstein motioned to recommend the approval of the data. Jonathan Teague seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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The sixteenth project reviewed by the Committee was:

**Project Title:** "Tracking the Well Being of Children in California"

**Principal Investigator(s):** Mark Mather, Population Reference Bureau

**Project Type:** New Project

**CPHS Approval:** Approved

**Project No.:** 12-12-1016

**Expiration:** February 28, 2014

**File(s) Requested:** 2011 Birth Statistical Master File (select variables)

**Requested Identifiers:** No Personal Identifiers

**Personal Contact:** No

**Identifiers Released:** No

**History:** New data request

**VSAC Discussion:** The requestor had mentioned needing death public use files, but this application mentioned birth files. They have asked if data from the Vital Statistics Query System could be released in a machine-readable format.

**VSAC Recommendation(s):** Approve the data request as submitted.

**VSAC Motions:** Jonathan Teague motioned to recommend the approval of the data request. Emily Putnam-Hornstein seconded the motion.

**VSAC Vote:** Committee members all voted in favor of recommending approval of the data request. There were no oppositions.

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**F. ITEMS FOR DISCUSSION:** Krista asked the Committee to refer to Item F, Recap of Data Requests Approved in the Vital Statistics Unit, Attachment 3. There were twenty-four data requests that did not require VSAC/VRPAC review were reviewed and approved by the Health Information and Research Section.

**G. PUBLIC COMMENT:** There were three members of the public attending the meeting.

- Lexi Gill speaking in behalf of Project #9, MIHOPE project. Lexi thanked the committee for their time and consideration of the application. She asked about the availability of data as it impacts the project. The request asks for vital records from 2010-2016. The data will be processed to meet congressional reports that bind them by specific requirements. They realized that they will be unable to receive the complete set of data. Krista informed her that we have provisional data that is available, but the charges for this will differ. The requestor was asked to send Krista an e-mail about her specific concerns. Krista told her that she can be on an announcement list, and she can reapply for the file, which would not require another VSAC review. Terri announced that the 2012 Death Statistical Master File should be ready this month. We are hoping to release both the Death Statistical Master File and Birth Statistical Master File at the same time. This will be the first year for an automated system for the Fetal Death Statistical Master File.
- Sun had a question about ICD10 codes regarding medical information on certificates to the state. Medical information is coded by NCHS; however, we have an employee with coding experience who verifies the NCHS entries. Terri will check with Jan Christensen regarding the coding process.
- Sun Lee asked about the Health and Safety Code pertaining to marital status. Krista told Sun Lee it is Health and Safety Code 102426.

- She also had a question regarding the release of information from the coroner's office as the Health and Safety Code specifies to whom it can be released to or to whom it can't be released to. Terri said she does not know the answer to this, what the coronary would release or not release about the decedent.
- Sun would be sending an e-mail to Krista as she would like copies of several protocols.
- Mike Luo  
Mike commented that in certain states, such as California, coroner reports are public records. As Mike was not able to sit in when his project was reviewed, Terri informed him that the committee approved his project with the stipulation that surviving members or others associated with decedents are not contacted and no personal identifiers would be released such as name and address. Vital Records are usually not used to contact living individuals of the decedents. Mike said that he explained in the request for the most part, they are trying to capture circumstances of these deaths in a comprehensive way across several states. Vital records are public in many states and don't need a committee review process. Most likely, his organization would avoid contacting live subjects, but may need additional information for case-specific details. He responded that they would abide by the decision to deny personal identifiers; however, the data would be useless to him as he would not be able to capture circumstances of deaths. He would not have knowledge on what type of weapon was used, where it occurred, and the age of the shooter. The point of getting vital records is to contact coroners' offices to get the coroner reports. The committee commented that the application that Mike has been referencing is not the materials that were posted on SharePoint, so they did not have all information. There were a couple of drafts after talking with staff on what they would be doing. In the application, he said that the records they would be requesting would not rely on contacting people and would rely on official records to capture various circumstances of death; however he may desire to contact surviving family members to understand circumstances surrounding the deaths better. Emily changed her recommendation after reading the revised application to approval of the release of the information. Jonathan Teague moved to reopen and revise the motion since the requester was not on the call when the project was discussed. Contact of decedent family members could open the state to liability and would require review by the Committee for Protection of Human Subjects. Mr. Luo commented that vital records are public in many states, and in some

states, you have to go through a committee review process to access birth records, but the same privacy provisions do not apply to death records. Terri mentioned the state's concern is not the decedents, but with living individuals associated with the decedents who may not want to be contacted. Mr. Luo thanked the committee for their time and considering the project.

**H. AGENDA ITEMS:** Krista asked the Committee if there were any agenda items for the next meeting. Jonathan suggested we include media requests on the agenda for the next meeting. Krista will add media requests and identifying information for contacting coroners.

**I. MEETING ADJOURNMENT:** Jonathan Teague motioned to adjourn the meeting. Emily Putnam-Hornstein seconded the motion. Committee members all voted in favor of adjourning the meeting at 11.11 A.M.