La Platica

Baca Family Historical Project Newsletter

Spring 2020

NEW MEXICO CHAPTER APPROVED!

Angioma Alliance Community

Ancestry's new test and Angioma Alliance Can ID the Common Hispanic Mutation

A NEW CHAPTER BEGINS

The Tale of Three Cristóbal's

Gutierrez Hubbell House Winter Conference 2019

Organizing A Conference, What It Takes!

MOTIVATIONAL SPEAKER BRIAN WAGNER

— Register for online webinar!

If You Could See What I See

June 2, 2020

WEBINAR

If You Could See What I See

Brian had a brainstem cavernous angioma. One day in 2011 at the age of 43, he woke up blind as the result of a hemorrhage. After six months of surgeries and procedures, a portion of his sight returned.

Only now, his vision is better than ever. He'll explain.

Brian will share with us his thoughts on embracing personal blindness to achieve a greater vision for life. He speaks at gatherings around the US, encouraging others to embrace their unique stories - we have much to learn from his experience.



Brian Wagner, Motivational Speaker

June 2, 2020 at 2 p.m. ET, 11 a.m. PT, 18:00 GMT

Please register at https://bit.ly/BrianWagner

CONTENTS

If You Could See What I See

Motivational Speaker Brian Wagner

2

The New Mexico Chapter
Angioma Alliance Community

Organizing A Conference, What 5 It Takes!

Ancestry's new test and
Angioma Alliance can ID the
Common Hispanic Mutation

Consensus Statement by the Angioma Alliance Scientific Advisory Board Regarding COVID-19 and Cavernous Angiomas

The Tale of Three Cristobal: 8
A new journey begins



The latest addition to the Baca Family Historical Tree. Evan James Gonzales born 5/12/2000. Yep! Joyce is a grandmother, again!

The Baca Family Historical Project is an initiative of Angioma Alliance, a 501c3 nonprofit organization. Our mission is to identify descendants of Cristobal Baca and Ana Maria Ortiz, one of New Mexico's founding families to bring together families and history for better health.

Connie Lee, Executive Director/CEO Angioma Alliance

Nora Chavez, Community Outreach Specialist, Baca Family Historical Project

Joyce Gonzales, Genealogist, Baca Family Historical Project

Visit our website at bacafamily.org

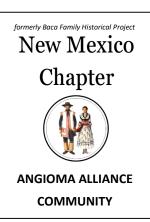
Call us a **505-450-5902**

6



Meet The New Board!

New Mexico Chapter of the Angioma Alliance Community Is Up And Running





Toby & Lori Arnett













Joyce Gonzales

Gallegos James & Sh

Candeleria Romero

Ashley Leyva

Lindsey Ramirez

The New Mexico Chapter of the Angioma Alliance Community held its first formal meeting in February. We at the Baca Family Historical Project are thrilled to continue our work with the support of this growing group of volunteers. The purpose of the New Mexico Angioma Alliance chapter is to increase awareness of cavernous angioma in the state, offer information to medical providers, support research participation, and raise funds for research and better care.

The Board was elected as follows:

Chair: Toby Arnett and Lori Arnett

• Vice-Chair and Grant Support: Candelaria Romero

Treasurer & NM Legislative Liaison: Joyce Gonzales

• Peer Support Co-Chair: Tim Gallegos

• Event Co-Chair: James & Sheri Baca

• Student Intern: Ashley Leyba

The Board is supported by Angioma Alliance Community Engagement Specialist Lindsey Ramirez and by Baca Family Historical Project Community Outreach Specialist Nora Chavez.

The Chapter is seeking more volunteers to help with outreach activities. Please join us! We need a wide variety of skills and representation from around the state as well as El Paso and southern Colorado. We need you to play a role in improving the quality of life for everyone with cavernous angioma.

The NM Chapter has started seeking grant funds to help support the costs of presentations, one conference each year, and mailings to medical providers. We expect to expand our activities as our volunteer base grows.

Fall Conferences 2020

Saturday, August 2, 2020 — Mini conference at National Hispanic Cultural Center, Albuquerque, NM. This mini conference is still on pending opening by the state for large crowd gatherings.

Sunday, August 3, 2020—2nd Annual Regional Conference. We will keep you posted on this conference to take place somewhere in northern New Mexico.

Organizing A Conference, What It Takes!



The backbone of every conference is its volunteers and an organized project manager. It can't happen without one or the other.

Our winter conference held on December 17, 2019, was planned in early January when a date was selected to have a conference in Albuquerque, NM. Nora Chavez, our Community Specialist had wanted to have one at the Gutierrez Hubbell House for over a year but dates were just not working out.

Then by chance, in early February, she tried one more time and, ta-dah! the skies opened up and all the stars were in alignment. A date was set where both Baca Family Historical Project, Angioma Alliance, and the Gutierrez Hubbell House could come together for a conference.

Meetings began with GHH Director, Elisabeth Stone. Quickly, Bernalillo County, which manages the open space known as Gutierrez Hubbell House, wanted to co-host the conference. More meetings, finding a guest speaker from GHH who would be willing to present on Josefa Baca, the matriarch of the Gutierrez Hubbell House, and more details. News releases were written, approved by Bernalillo County, and sent off to the media. Flyers and brochures were designed and produced. Radio interviews were arranged for Nora and Joyce Gonzales, our genealogist, could talk about the conference and about the DNA testing we would provide to participants.

As time grew near, volunteers were recruited to help with set

-up and break-down, registration, photography, and refreshments.

The conference was a huge success and we owe a lot to our presenters and volunteers:

- Flora Sanchez, presenter, Josefa Baca Genealogy
- Joyce Gonzales, presenter, Tale of Three Cristóbal's
- Connie Lee, presenter, Understanding CCM1
- Dr. Javed Eliyas, BJ S, Toby & Lori Arnet, Panelists
- James Baca, Volunteer
- Toby & Lori Arnett, Volunteer
- Candeleria Romero, Volunteer
- Rhonda Vigil, Volunteer

We love you all!



Latest information on testing for CCM1 gene mutation

Ancestry's new test and Angioma Alliance can ID the Common Hispanic Mutation

During this time of COVID-19, Angioma Alliance, parent organization of the Baca Family Historical Project, has put its genetic testing program on hold. We have been concerned about limited access to follow-up care for those with a positive result, and we have had virus-related budgetary constraints.

For those of you who need genetic testing specifically for the Common Hispanic Mutation and are unable to secure it through your doctor, an alternative is available through Ancestry DNA. While Ancestry DNA will not directly tell you whether you have the Common Hispanic genetic mutation,

their most recent tests provide raw data that include the relevant portion of the CCM1 gene. This data can be used at a different website, Promethease, to determine your mutation status.

Angioma Alliance receives no compensation from Ancestry, Ancestry DNA, Ancestry Health, or

Promethease. We are providing this information entirely as a resource. We claim no responsibility for the quality or outcome of Ancestry DNA testing, their use of your DNA data, or Promethease's analysis and use of your data.

Before using Ancestry DNA to determine your or your child's genetic mutation status, please read

through the Why Get Testing? portion of the Angioma Alliance website at http:// angioma.org/ pages.aspx? content=434. There are both benefits and risks to finding out your mutation status. It's important to understand these and to have a plan should your result

be positive for the

mutation.



If you are ready to order the Ancestry DNA test and follow through with testing and data analysis, please visit our website for instructions at http://angioma.org/pages.aspx?content=513.

Consensus Statement by the Angioma Alliance Scientific Advisory Board Regarding COVID-19 and Cavernous Angiomas

Updated April 28, 2020

The Angioma Alliance Scientific Advisory Board continues to monitor any specific reports or emerging concerns about COVID-19 and cavernous angiomas. To date, there is no evidence that cavernous angioma patients will be affected differently by this pandemic than other patients of similar age, medical co-morbidities and levels of disability. We are aware of reports of stroke in young patients, excessive clotting and other neurologic manifestation of COVID-19, but it remains unclear how these may impact cavernous angioma patients specifically.

Until further evidence arises, patients with cavernous angiomas with recent bleeds in the past year and associated new neurologic symptoms, surgery on the brain or spine in the past 6 months, persistent neurologic disability from prior bleeds, or active seizures may be a group considered as having a comorbidity, and are potentially at higher risk with COVID-19. This is in addition to other cases designated high risk by the Center for Disease Control (CDC) because of age 65 years or older, heart disease, chronic lung conditions, immunocompromise, pregnancy, or diabetes. In the last month, the CDC has added severe obesity (BMI>40), chronic kidney disease undergoing dialysis, and people with liver disease to the high-risk category.

For high-risk individuals, it is important to adhere to social distancing, disinfection of the environment, wearing facial masks in public, and practicing hygiene per CDC guidelines. It is also important to avoid contact with individuals (including family and caretakers) exposed to COVID-19, recently traveling back from areas heavily affected by the disease, or exhibiting fever or other flu-like symptoms, until those persons prove negative testing for the COVID-19 coronavirus, or until 14 or more days after their exposure, travel or last symptoms. Travel avoidance is recommended, unless absolutely necessary, until travel advisories related to COVID-19 are lifted. Caregivers and those individuals who are sharing a home with high-risk cavernous angioma patients should follow the same precautions.

We encourage patients to not delay medical care or imaging for cavernous angioma if recommended by your physician, including necessary travel for medical care and timely evaluation if new neurologic symptoms arise. Patients should continue their seizure medications, and other medications for medical conditions, and notify their cavernous angioma doctors about any positive test for COVID-19. It is recommended that patients in clinical trials continue to adhere to ongoing trial procedures and notify their trial investigators about positive testing for COVID-19.

We also urge any patient with known cavernous angioma of the brain or spinal cord, who has tested positive for COVID-19, to report to our CCM COVID-19 Registry. A family member or caretaker may report on behalf of a sick or diseased patient. You will be contacted back by a research coordinator for a telephone consent and questionnaire about your COVID-19 experience in relation to cavernous angioma.

Dr. Issam Awad, Chair, Angioma Alliance Scientific Advisory Board University of Chicago Neurosurgery

Dr. Kelly Flemming Mayo Clinic Rochester Neurology

Dr. Kevin Whitehead University of Utah Cardiology

Dr. Rustam Al-Shahi Salman University of Edinburgh Neurology, UK



A Tale of Three Cristóbal's by Joyce Gonzales

Revised October 2019

Cristobal I: Progenitor of Baca Family

Cristobal Baca (1567- 1613) was the Progenitor of the Baca Family in New Mexico and the South West.
Cristobal was a Captain born in Mexico City, New Spain.
He and his wife Ana Ortiz (1563-1620) and their children came to New Mexico in 1600 with other reinforcement soldiers. These soldiers were sent to help protect the newly established Spanish Colony set up by Juan de Onate in 1598 at Ohkay Owingeh (formerly San Juan Pueblo).

Henrietta Christmas, President of the New Mexico Genealogical Society, has estimated that there are about five million descendants from Cristobal Baca and Ana Ortiz. Almost any person who has seven or more generations in New Mexico will descend from one of the many Baca lines, if not several times.

Cristobal II: Possible Father of a founding grandparent of ***CCM1

Cristobal Baca II (1625-1697) was the grandson of Cristobal I. Cristobal II was the father of Manuel Baca. Research identifies Manuel Baca or his wife Maria Hurtado de Salazar (1656-1730) as the possible *Founding Grandparent of

**Cerebral Cavernous Malformations (CCM1), also called the Common Hispanic Mutation (CHM) in New Mexico and the Southwest. At this time, we do not know of any other children of Cristobal II who carried the mutation.

Manuel Baca and Maria Hurtado de Salazar had nine known children. Research to date has identified at least four of these children who probably had the CCM1 mutation. Maria Josefa Baca (1685-1746) was one of those probably affected children. Josefa had six children, several of whom probably had CCM1.

Cristobal III: Probably had the highest number of descendants with CCM1

Cristobal Baca III was the son of Manuel Baca and Maria Hurtado de Salazar. He was married to Apolonia de la Vega y Coca (1701-1734) and Maria Manuela Marquez. Research indicates that Cristobal III probably had CCM1. This Cristobal probably had the biggest impact on families affected with CCM1 because of the sheer number of children that were born into his family. Cristobal III had fifteen known children with his two wives, and his grandson Luis Maria Cabeza de Baca had twenty- three known children with 3 wives.

I have only followed one line which includes three family members with the name Cristobal Baca. As research continues, the validation team will continue to add more identified lineages.

We are also following the Dominguez de Mendoza family from which most of the CCM1 families from Mexico trace. For example, I have CCM1 and I go back through both the Baca and the Dominguez de Mendoza families. Therefore, I could have inherited CCM1 from either one of these families.

Research to date has identified at least two children of Cristobal III who probably carried the CCM1 mutation. These children were Maria Agustina Baca married to Antonio Armenta and Juan Antonio Baca married to Maria Romero (de Pedraza).

Juan Antonio Baca married Maria Romero and they had ten known children. Research to date indicates that five of their sons probably had CCM1. They were:

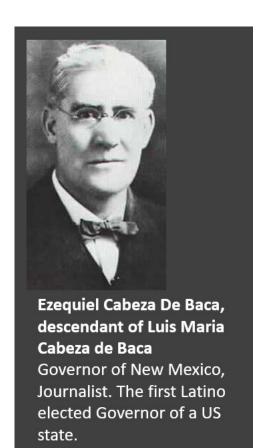
Jose Maria Baca (1761-)

Jose Miguel Baca (1765-)

Jose Manuel Baca (1767-1713)

Juan Esteban Baca (1768-)

Luis Maria Cabeza de Baca (1754-1827)



Luis Maria Cabeza de Baca was the grandson of Cristobal Baca III.

Luis acquired several land grants, one of which was in Las Vegas, New Mexico. Some believe that he and his family were descendants of the Spanish explorer Alvar Nuñez Cabeza de Vaca. Although this theory has not been proven,

Luis Maria changed his and his children's surnames to Cabeza de Baca

Luis had approximately 23 known children with three wives. Luis Maria was killed in 1827 for harboring a fur trapper. Most of the children of Luis Maria went on to have their own large families many of who probably had CCM1. We know that this illness does not skip generations and that each of his 23 children had a 50% chance of inheriting CCM1. If approximately half of Luis Maria's children inherited this illness, then the impact this family had on the CCM1 gene mutation would have been huge. The grandchildren of Luis Maria and their descendants abbreviated their surname from Cabeza de Baca to C'de Baca. We know that all C'de Baca today descend from Luis Maria Cabeza de Baca. Much more research will need to be done on this specific family line to identify more of Luis Maria's affected children. Research to date has identified at least two of Luis Maria's children who probably had CCM1. They were:

Juan Antonio Cabeza de Baca (1783-1835)

Prudencio Cabeza de Baca (1800-)

In the case of Prudencio Cabeza de Baca, he either married twice or there are two men with the same name. This is not uncommon in this family; Luis named several of his children Antonio after his father. Research to date has identified at least one of Prudencio's children who probably had CCM1. This child was: Valentine C'de Baca (1861-1911) who married Elvira Gallegos (1859-1938) and lived in Peña Blanca, NM. Valentine C'de Baca and Elvira had fifteen known children. Research to date has identified at least four of these children that probably had CCM1.



New Mexican Surnames Possibly Affected by the CCM1 Common Hispanic Mutation (to date)

Apodaca Gallegos **Padilla** Quintana Aragon Garcia Armijo Gonzales Rivera Baca Lopez Romero C' de Baca Sandoval Lucero Campos Silva Luna Sais/Saiz Casaus Maes/Maez (Maese) Chavez (Duran y Martinez Vigil

Chavez) Mora Espinosa/Espinoza Ortiz

Mexico Surnames Possibly Affected by the CCM1 Common Hispanic Mutation (to date)

Aguirre Mendoza Chavez (Duran y Perez

Chavez)Contreras Ponce (de Leon)

Dominguez Rascon
Domingez de Mendoza Vejar

Grijalva

Baca Family Historical Project

3201 Zafarano Dr, STE C-363 Santa Fe, NM 87507



FUNDERS









PROGRAM PARTNERS









