

# **EYE** *of the* **TIGER**

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## **C A M P A I G N**

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“Perhaps you were put in this position for a time such as this.”

Esther 4:14

This campaign's purpose is to raise money and awareness to determine the cause and eventual cure of Ocular Melanoma.

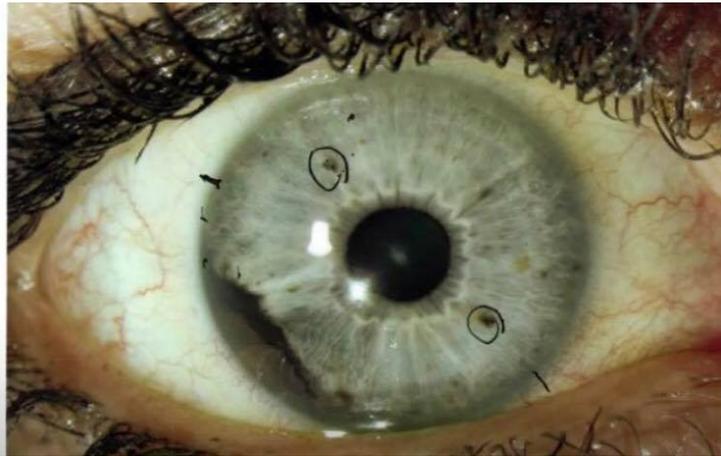
Contact:

Ashley Holmes McCrary // [amccrary1@bellsouth.net](mailto:amccrary1@bellsouth.net) | 334-728-5358

Courtney Mackinaw Redmond // [clmr76@gmail.com](mailto:clmr76@gmail.com) | 706-254-8666

We respectfully ask the Governor's office, our city and state officials, and philanthropic donors to prayerfully consider contributing to this campaign. The time for this research is now and we are confident the research will advance the diagnosis, treatment and possible cure of this rare disease known as Ocular Melanoma.

## Introduction to Ocular Melanoma



Ocular Melanoma is a cancer of the eye involving the iris, ciliary body, or choroid (collectively referred to as the uvea). Tumors arise from the pigment cells that reside within the uvea giving color to the eye. When eye melanoma is spread to distant parts of the body, the 5-year survival rate is about 15%. This disease typically affects 6 out of a million people. 2,500 people a year are diagnosed. According to the Alabama Department of Public Health, Alabama has the highest incidence of Ocular Melanoma of any state. Since 2017, 50 people have come forward who have this rare disease and have an affiliation with Auburn University.

## Of those who self-reported, this is what we know:

Dr. John Mason has verified 28 are male and 22 are female. Despite the rumor that all 50 patients lived on campus, only 8 females did. The time span when these people attended Auburn or were in the Auburn University area ranges from 1958-2010. There were peaks in attendance between 1976 & 1979 (5 people) with the greatest number attending between 1980 & 1998 (31 people). Of the group from Auburn, seven have had their causes of death attributed to metastasis of Ocular Melanoma. Lastly, the mean age of this cancer's diagnosis is 65; In Auburn the mean age of diagnosis is 42.

## 50 people...rare cancer...at least two things in common.

Fifty patients have self-reported Ocular Melanoma diagnoses as of April 2019. Each patient reported one of the following affiliations with Auburn University: They were either a student, faculty or staff member, or associated with a person who was in one of those categories.

1. M. McWilliams
2. J. Greene
3. A. McCrary
4. A. Armistead
5. L. Lee
6. S. Muro
7. A. Lynch
8. J. Wiggins
9. J. Hurst
10. S. Holt
11. B. Haynes
12. J. Burns
13. B. Kaiser
14. J. Russell
15. S. Wester
16. D. Wooten
17. S. Wonderlich
18. D. Mohon
19. D. Gropper
20. A. Wright
21. C. Redmond
22. J. Neher
23. P. Stroud
24. F. Innes
25. R. Wiggins
26. J. Callaway-Harris
27. C. Graham
28. K. Murphy
29. M. Johnson
30. G. Brinkley

31. R. Singletary

32. C. Norris

33. Z. Edwards

34. J. Terrell

35. M. Espy

36. G. Cain

37. T. Hurst

38. R. Logan

39. M. Davis

40. S. Jean

41. M. Johnson

42. C. Russell

43. C. Adams

44. D. McLaughlin

45. T. Martin

46. J. Bradshaw

47. H. Dudley

48. S. Harper

49. A. Hollingshead

50. B. McAllister



## Meet a few of the Auburn OM advocates:

These are just 5 of the 50 people that have these two things in common: A very rare disease known as Ocular Melanoma and Auburn University. In 2016, Ashley, Juleigh, and Allyson received messages on social media that Mark McWilliams, age 42, a graduate of Auburn University in the School of Architecture had passed away due to metastasis of Ocular Melanoma. His wife, Susan, had read that there were other cases associated with Auburn so she reached out to the Ashley, Juleigh, and Allyson via social media. The three women shared their stories with her and through sharing their stories with others, over the course of a year an additional 46 people came forward.

Here are their stories.



## Mark McWilliams

Mark graduated from Auburn in 1994 with degrees in architecture and building science; He was an architect at Birchfield Penuel & Associates, in Birmingham. He spent a great deal of time figuring out how things work and how to make them better. He was a wonderful husband to Susan Roberts McWilliams, a wonderful son to Edgar and Vonnette McWilliams, and a wonderful brother to Lisa McWilliams Ortman. He was diagnosed with OM in 2011, and he succumbed to this disease in 2014. It was Mark's wife and friends reaching out through social media that sparked the Auburn Ocular Melanoma Facebook Page.



## Juleigh Little Green

Juleigh was diagnosed first in 2000 when her first child was 6 weeks old. She had symptoms for a year that included flashes of light and blurred vision. When she was finally diagnosed her only course of treatment was enucleation (removal) of her eye. While she has not had metastasis of Ocular Melanoma, she was diagnosed with Pancreatic Cancer a few years ago and is proof that God is a Healer. Juleigh has been married 23 years, has two children and is a teacher in Vestavia Hills, Alabama. Juleigh's oldest daughter currently attends Auburn. Juleigh attended AU from 1989-93.



## Allyson Armistead Allred

Allyson Allred was diagnosed in 2001. She was a friend of Juleigh's and will tell you that Juleigh walked her through a very difficult time in her life. Like Juleigh, Allyson had flashes of light and discoloration in her vision. She learned the reason she was having flashes of light was a 10mm tumor sat on her retina. Like Juleigh, she had to have her eye removed. She remained cancer free for seven years. Within the last 11 years the cancer has returned to her liver, breast, ovary, adrenal gland, diaphragm, kidney, spine, colon and her brain. Her treatments have taken her to Philadelphia, PA and to numerous radiation treatments in Birmingham. She attributed her ability to fight this cancer to the strength from the Lord. Sadly, Allyson passed away April 24, 2019 after battling this horrible cancer for 18 years. She is survived by her husband, John, their 2 children Lindsey and John David, her father, Bill Armistead and her brother, Beau. She was a true warrior and advocated for those with Ocular Melanoma. Allyson always remained positive and exuded the love of her Savior to all who met her. She attended AU 1988-92. We are even more determined to find a cause and a cure to honor her and her legacy.



## Ashley Holmes McCrary

Ashley McCrary was diagnosed in 2012 while living in Memphis, TN. After a friend asked her about a "spot on her eye" she had a thorough eye exam which revealed a tumor. She was sent to an Ocular Oncologist who removed her right eye and sent it off for testing. She was diagnosed with a Class II tumor known as a Ciliary Body Melanoma, which is included in the grouping of Uveal Melanoma. A Class II tumor is an aggressive type that will likely metastasize. Peak metastasis is 7 years from diagnosis; It has been 7 years for her. Ashley has been married for 27 years, has four children (one of whom is a Junior at Auburn) and since 2015 has lived in Auburn. Ashley attended AU from 1988-92.



## Lori Lee

During a routine eye exam in 2011, Lori Lee's doctor found a freckle on her eye. Two years later it turned into Melanoma. She was treated with 3 laser treatments over 3 months in the hopes of killing the tumor and saving Lori's sight. Unfortunately, in 2017 the cancer metastasized to her liver. She tried 2 different treatments neither of which worked. She is now fighting for her life in Philadelphia where she is participating in a clinical trial. She must travel to Philadelphia every six weeks to undergo treatment, scans and attend appointments. As you can imagine, this is very hard on her physically, emotionally and financially. Lori has been married for 9 years to her husband Bruce and they live in Guntersville. Both of her children attended Auburn. She was a pharmacy student at AU from 1986-89.

## Explanation of research in the words of Dr. John Mason:

An unusually high number of people have developed ocular melanoma that spent some time in the Auburn area. Up to 50 percent of patients who develop this cancer die. There are two possibilities. One, that it is a random occurrence and not truly a "cluster." Or, it is a "cluster" that may have an environmental trigger causing the melanoma. The only way to know is to perform a study. To date worldwide, no environmental trigger has been found causing ocular melanoma. I, Dr. John Mason, am an expert in this field and feel that this is a potential health crisis in our state. The study will evaluate the past environment and exposure of each patient as well as test each patient for genetic mutations. This study must be done to provide answers. The answer could be that nothing in the Auburn area contributed in any way to developing melanoma, and that this was a random occurrence. A smaller probability could exist that an environmental trigger caused patients to develop melanoma, which would then allow us to prevent this trigger going forward, thereby preventing people from dying. To perform a study of this magnitude requires a task force with specialists. I am happy to lead this task force altruistically. I am the only Eye Cancer specialist in the state of Alabama (Associate Professor, Director of Retina Fellowship UAB). The following members are also needed: Dr Fred Kam (Auburn University Medical Director), John Cassels, Geospatial Analyst, Dr. Scott Harris and Justin George with the ADPH, Dr. Takami Sato and Dr. Marlana Orloff of Thomas Jefferson University,

Dr. Miguel Materin of Duke University, Dr. Rich Carvajel of Columbia University, Dr. Mike Brennan Consultant from research conducted in Huntersville NC, and the Hudson Alpha Company in Huntsville,AL. This study will require three components:

1. Epidemiologist and cancer registry experts from ADPH (Dr. Harris and Justin George)
2. Geospatial and environmental experts (John Cassells)
3. Genetic experts in the field of eye cancer (MDs listed above).

I, Dr. Mason, have assembled this team and will lead these experts in a world class study which has never been done correctly in this area of cancer and medicine.

Oversight and appropriation of funds will be through the Community Foundation of East Alabama and a board of 5.

Funding required would be approximately \$270,000

Epidemiology and Cancer registry study - completed by ADPH

\$75,000 for Geospatial and environmental testing

\$195,000 for Genetic testing for eye cancer mutations and tumor suppressor gene mutations in blood and residual banked tumor from all patients.

A 501-c3 was set up to make tax deductible donations through the Community Foundation of East Alabama. A person can donate at either [eyepatchchallenge.org](http://eyepatchchallenge.org) or at [tcfeastalabama.org/contact-us/](http://tcfeastalabama.org/contact-us/)

## The ADPH findings and Auburn's response:

Although no cancer cluster was definitively found by the Alabama Department of Public Health, after a meeting of the scientific experts and other interested participants in February and April 2019, it was decided to do both a geospatial analysis and genetic/tissue testing. The full FAQ response can be found here: <http://ocm.auburn.edu/news/uvealmelanoma-faq/>

## Research proposal moving forward:

A round table discussion was held in Auburn February of 2019. In attendance were: Dr. John Mason (Ocular Oncologist/Ophthalmologist in Birmingham), Dr. Fred Kam (Auburn University), Dr. Takami Sato (Thomas Jefferson), Dr. Marlana Orloff (Thomas Jefferson), Dr. Mike Brennan via Skype from North Carolina, Bill Armistead (Father of Allyson Allred), Lori Lee (OM survivor and advocate), Juleigh Greene (OM survivor and advocate), and Ashley McCrary (OM survivor and advocate). The discussion was led by

Dr. John Mason who is leading the research efforts. This meeting was called to determine research protocols. It was decided the study would only include patients with ties to Auburn University from 1980 to the present. The number of people to be included is 33. As of March 19, 2019, 30/33 patients have confirmed their participation in the study.

As stated above, the cost per patient for the geospatial analysis and the genetic arm of the research is expected to be approximately \$8,000- \$9,000 at a total cost of approximately \$270,000. At this time the University has agreed to pay for the geospatial analysis which is expected to cost in the upward of \$75,000. This leaves a balance of \$195,000. The Auburn Ocular Melanoma Group has raised \$63,000. **Therefore, \$132,000 is needed to complete this project.**

## Auburn OM National Media Attention:

Over the past year the national media attention has included *The CBS Morning Show*, *NBC Nightly News*, *NBC Today Show*, *People Magazine*, *Dr. Oz*, local TV coverage all over the state of Alabama and has been syndicated all over the world in both TV coverage and in print. As of October of 2019, an analyst reported this story reaching 3.7 billion people. This deserves the attention and support of our state and local governments.

## Similar research being conducted in Huntersville, NC

In 2015 the state of North Carolina allotted \$100,000 for research to occur in Huntersville, NC where a group of 18 residents of Mecklenburg County were diagnosed with OM. Here are some articles on the research there:

<https://www.wcnc.com/article/news/investigators-release-eye-cancer-findings-in-huntersville/275-540363436>

[https://www.wcnc.com/article/news/health/nc-bill-filed-would-put-100000-toward-solving-huntersville-ocular-melanoma-cluster-mystery/275-33a28556-9b47-4750-b243-31bb21d6c8a5?](https://www.wcnc.com/article/news/health/nc-bill-filed-would-put-100000-toward-solving-huntersville-ocular-melanoma-cluster-mystery/275-33a28556-9b47-4750-b243-31bb21d6c8a5?jwsourc=fb&fbclid=IwAR3rBu0JbqD8N_o2D27Lh3ZAlrCWQeSJPgpyaBZ19IoOrTByEGGb5jwyWmg)

[jwsourc=fb&fbclid=IwAR3rBu0JbqD8N\\_o2D27Lh3ZAlrCWQeSJPgpyaBZ19IoOrTByEGGb5jwyWmg](https://www.wcnc.com/article/news/health/nc-bill-filed-would-put-100000-toward-solving-huntersville-ocular-melanoma-cluster-mystery/275-33a28556-9b47-4750-b243-31bb21d6c8a5?jwsourc=fb&fbclid=IwAR3rBu0JbqD8N_o2D27Lh3ZAlrCWQeSJPgpyaBZ19IoOrTByEGGb5jwyWmg)

In March and April of 2019, North Carolina's House and Senate have presented bills to request funding for research in Huntersville, NC:

[https://www.ncleg.gov/BillLookUp/2019/S277?  
fbclid=IwAR1VhwZdO11yl2O91jbS5BRFB4rU5AOSam9B5PUIZ\\_CGTGRgigkQ3kWUoTE](https://www.ncleg.gov/BillLookUp/2019/S277?fbclid=IwAR1VhwZdO11yl2O91jbS5BRFB4rU5AOSam9B5PUIZ_CGTGRgigkQ3kWUoTE)

<https://www.ncleg.gov/BillLookUp/2019/H640>

**For more information about Uveal Melanoma please visit the following websites:**

[National Cancer Institute Intraocular Melanoma for Patients](#)

[National Cancer Institute Intraocular Melanoma for Health Professionals](#)

[National Institutes of Health Guide on Ocular Melanoma](#)

[American Cancer Society Guide on Eye Cancer](#)

[The Ocular Melanoma Foundation](#)