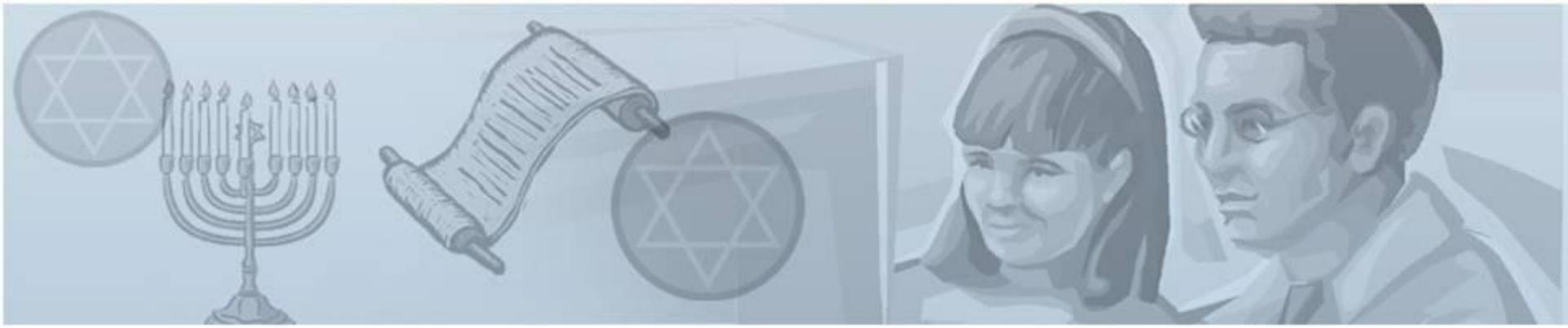


# Public Health Education in Jewish Culture: Tay-Sachs Screening and Prevention

Anthony Wallace  
Capella University  
DRPH 8110 History and Theory of Public Health  
Dr. Ray Borges, DHA, PhD  
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# Introduction

A decorative header image featuring several elements: a Star of David (Magen David) on the left, a menorah in the center, a scroll with a quill pen, another Star of David on the right, and a woman and a man looking towards the right in the background.

- Health care education and outreach should have a tailored tier structure to the delivery method within the targeted community.
- Culture awareness should be the essence in all presentations, outreach programs, and treatments to Jewish community members.
- Education or prevention techniques should enable practitioners to approach health disparities with systematic modern theory and employ action research modeling in discovering new methodologies.
- The focus of this presentation is to make the public aware of the prevalence of Tay-Sachs disease (issue) in the Jewish population and determine how modernized systems theory may present theoretical answers in action research (solution).

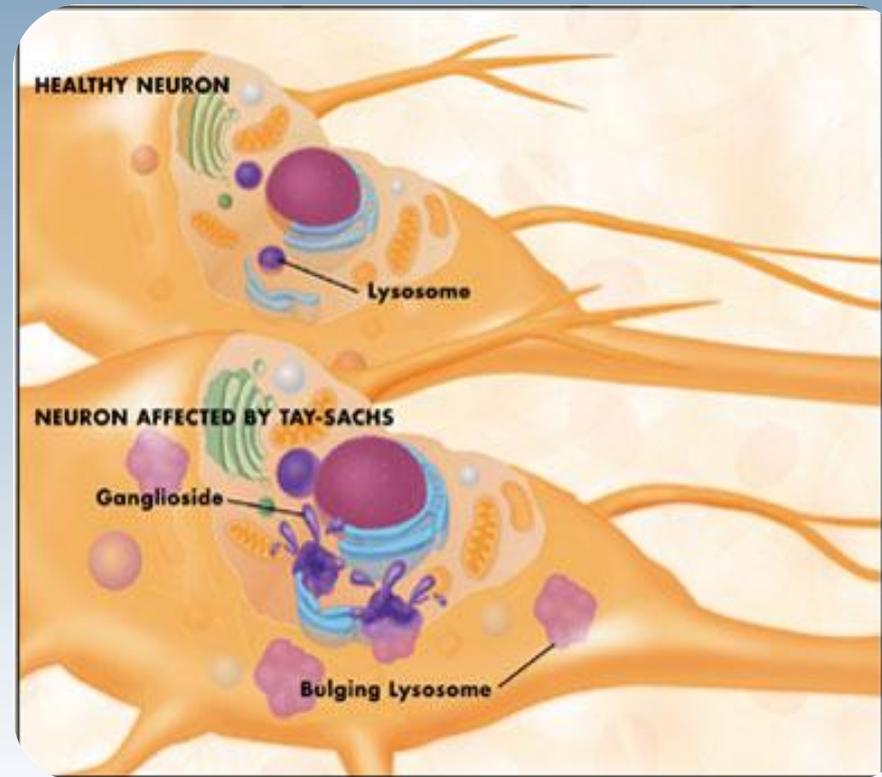
# Overview

A decorative header image featuring several elements: a Star of David (Magen David) on the left, a menorah in the center, a scroll with a quill pen, another Star of David on the right, and a close-up of a young girl and a man's face on the far right.

- The essay presentation will target the prevalence of Tay-Sachs disease in the Jewish population.
- The essay will discuss relevant action research modeling in preventing and treating Tay-Sachs disease.
- The essay will review the pathology of Tay-Sachs disease, symptom management, and propose screening prevention programs aimed to reduce the incidence of Tay-Sachs disease within the Jewish community.

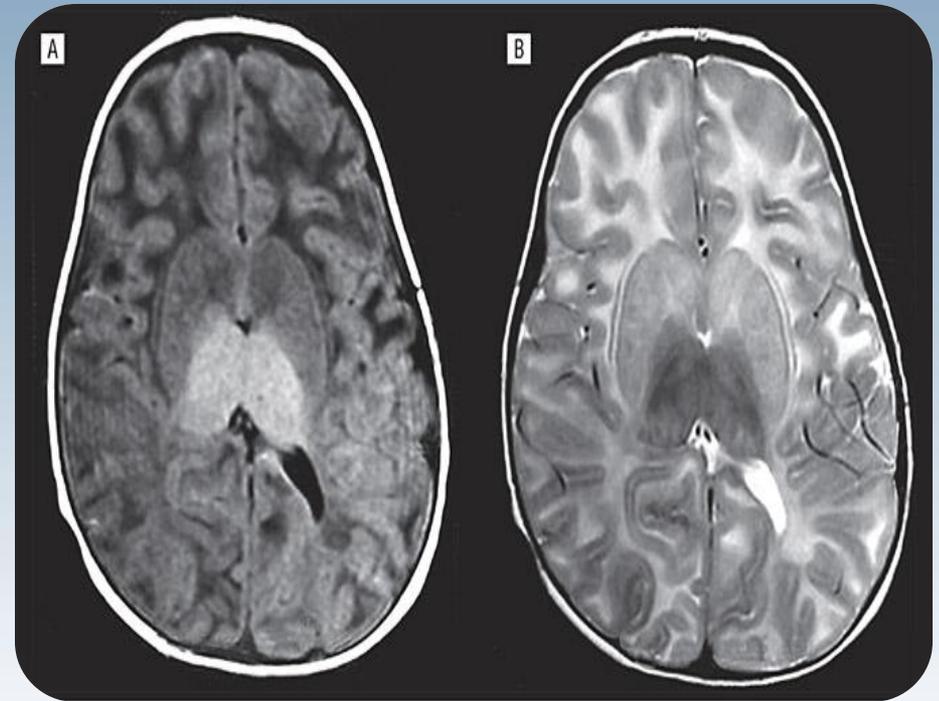
# What is Tay-Sachs Disease?

- Tay-Sachs disease is a lack of HEXA MIM enzyme, which prevent the build up of GM2 ganglioside as shown here in the picture (Lew; Burnett; Proos, 2011). The over production of this protein may cause excessive brain damage



# Pathology of Tay-Sachs Disease

- The brain that is located on the right is a normal child's brain.
- The brain on the left is a brain that is calcified with protein with significant brain damage. The white portion with enlargement of the tissues is an indication of Tay-Sachs.



# Symptomology of Tay-Sachs

- Deafness
- Decreased Eye Contact
- Decreased Muscle Tone
- Dementia
- Irritability
- Loss of Motor Skills
- Seizures
- Slow Growth
- Increased Startle Reaction
- Listlessness (A.D.A.M., 2013)





# Symptomology Cont:

- Depending on the age of the patient, the symptoms may lay dormant until late adulthood >40 years.
- Tay-Sachs disease occur in less than 200,000 people in the United States of America. Only 1:2000 children are affected by Tay-Sachs disease (Rightdiagnosis.com, 2014)
- Symptoms may include
  - Dysathria
  - Ataxia
  - Spasticity
- Treatment (Tx) for Tay-Sachs may include stem cell implantation, genetic counseling, and medication to make the patient comfortable (NIH, 2014).



# **M&M OF TAY-SACHS DISEASE IN JEWISH POPULATIONS**

# Infantile Tay-Sachs Disease

- Tay-Sachs is a rare disease that when tested, only 1:2000 children may contract the disease
- Infantile Tay-Sachs is classified in babies who are less than six months old (Taysachs.com, 2013)



# Juvenile Tay-Sachs Disease

- Juvenile Tay-Sachs is rare among the population but is seen in children at the age of two and ten years of age.
- Symptoms may include dysrthria, ataxia, and spasticity (Taysachs.com, 2013).



# Adult Onset Tay-Sachs Disease

- Symptoms in adults being to show at the age of 30-40 years old.
- According to Tay-Sachs.com (2013), symptoms are not considered fatal because of the growth of the brain and tissues. The patient has reached chronological age in which the brain has matured.





# Health and Wellness Screening

- According to Metcalfe (2012), screening for Tay-Sachs in the Jewish population only occurs during routine prenatal visits. Screening will give the parents freedom to assess the risk factors and make the difficult decision to accept or terminate the pregnancy.
- Prevention screening may save expecting couples money, time, and traumatic emotions when deciding to conceive a child.
- Public health practitioners may incorporate blood test drives, genetic counseling, and social services for those families who are caring for children with Tay-Sachs disease.

# Systematic Approach to Public Health



- The systematic approach is quite simple, public health practitioners must incorporate computers by monitoring prevalence rates among the targeted populations i.e. Jewish Tay-Sachs disease.
- An example of systems approach within the action theory Orem is the adaptive visualization of e-sciences (Advise).
- Employing modern technology into public health practice may prove or disprove old theories, pinpoint proposed program objectives, store prevalent data for future use; provide evidence of emergency resourcing to areas of high risk for Tay-Sachs.
- Modernized practice may provide data pathways for action research, which may further research and/or provide room for governmental funding opportunities for prevention and treatment programs

# Action Research



- Action research will allow Jewish leaders to inform their communities regarding public health screening for Tay-Sachs.
- Action research is an approach to research which aims at both taking action and creating knowledge or theory about that action (Ennals, 2009).
- Action research will allow technical knowledge to become practical; therefore, the explanation may be less dense and more digestible for those who do not have a medical or scientific background.

# Health and Wellness Resourcing



- According to Altman; Inman; Stephanie; Ritter; Howard (2010), the Jewish population is considered as an invisible minority who are classified as White Americans.
- Many Jewish communities may not receive social services because of their racial classification.
- Public health practice must address culture dynamics within the community, which gives the historically challenged population their global identity as minorities.
- Prevention practices and treatments may improve the health outcomes for Tay-Sachs patients and promote the quality of life for those who are involved in the patient's care plan.

# Health and Wellness Resource Links

- Follow the links below to access education regarding Tay-Sachs disease.
- Rightdiagnosis.com. (2014). Tay-Sachs disease, Retrieved from: [http://www.rightdiagnosis.com/t/tay\\_sachs\\_disease/intro.htm](http://www.rightdiagnosis.com/t/tay_sachs_disease/intro.htm)
- NIH. (2011). What is Tay-Sachs?, Retrieved from: <http://www.ninds.nih.gov/disorders/taysachs/taysachs.htm>
- National Tay-Sachs and Allied Disease Association. (2014). Tay-Sachs, Retrieved from: <http://www.ntsad.org/index.php/the-diseases/tay-sachs>
- The agencies which are listed may provide further information regarding social services to Tay-Sach patients



# Conclusion



- Tay-sachs is a disease that is mostly found in Irish and Ashkenazi Jewish communities.
- Public health practitioner may incorporate modernized systems theory to track, prevent, and treat those children and adults who have contracted Tay-Sachs disease.
- Screening programs are paramount in reducing the number of Tay-Sachs births. Government intervention such as funding programs to provide free genetic counseling to low and middle income Jewish decent couples may also reduce the prevalence of Tay-Sachs births.
- My research proposal is to conduct action research using modernized technology, community drivers, and collaborating services i.e. Tay-Sachs societies to raise awareness in efforts to prevent Tay-Sachs births.

# References

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- Metcalfe, S. (2012). Carrier screening in preconception consultation in primary care, *Journal of Community Genetics* 3(3), pp. 193-203, doi:10.1007/s12687-011-0071-2
- Altman, A., Inman, A., Stephanie, G., Ritter, H., Howard, E. (2010). Exploration of Jewish ethnic identity, *Journal of Counseling and Development: JCD* 88(2), pp. 163-173

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- A.D.A.M. (2013). Tay-Sachs disease, PubMedHealth, United States National Library of Medicine, Retrieved from <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002390/>.
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- Tay-Sachs.com. (2013). Tay-Sachs disease online facts and information, Retrieved from <http://www.taysachsdisease.com/>.
- Pictures and illustration used in this presentation were extracted from Yahoo.com.