Swedish American Genealogist

Volume 33 Number 3 Article 12

9-1-2013

Was it Batten disease?

Janice Asp

Follow this and additional works at: https://digitalcommons.augustana.edu/swensonsag



Part of the Genealogy Commons, and the Scandinavian Studies Commons

Recommended Citation

Asp, Janice (2013) "Was it Batten disease?," Swedish American Genealogist: Vol. 33: No. 3, Article 12. Available at: https://digitalcommons.augustana.edu/swensonsag/vol33/iss3/12

This Article is brought to you for free and open access by Augustana Digital Commons. It has been accepted for inclusion in Swedish American Genealogist by an authorized editor of Augustana Digital Commons. For more information, please contact digitalcommons@augustana.edu.

Was it Batten disease?

By Janice Asp

1866 års Död- och Begrafnings-Bok			för Lomaryd Moder Församling.			
Begrafnings Kön.	D e a f l i d n e s namn, stånd, embete, yrke, hemvist, nationalitet och trosbekannelse (om fråmmande), samt för minder- åriga, föråldrars namn, yrke och hemvist.	Ar. Månad. dag enkling, cala	Dödsorsak.	Döde i välgörenhets-, sjukvårds-, straff-	Faile at Bus- Richtesbakes.	Serskilda Anteckningar.
24 Lept 2 1	Tig. Emilia Eva Sofia Swenses Fran S. Ralingias Norry.	21 1. 11. Ogiff	Fallande Sof.		196 7/4	I fallande det ah warit be
	from J. Ralingsas Morry.				Jest	I fallande det och ward to on gen was ste ar gamme

Lommaryd C:6 (1861-1882) Bild 236, (picture from Arkiv Digital). The text to the right says that Emilia had had epilepsy and been blind since she was 8 years old.

George Swanson was the maternal grandfather of my mother-in-law, Eleanor Carlson Asp. His birth was February 24, 1848, in Sweden. The place was Södra Ralingsås Norrgård in the parish of Lommaryd in the county of Jönköping. Named Göran Peter, he was the youngest of 10 children born to Swen Persson and Anna Gustava Ingesdotter.

It was easy to trace this family in the clerical surveys, since all the children were born in the same place beginning in 1824. It was noted that child 2, Johanna Gustava born 1826, and child 3, Christina Charlotta born 1828, were listed as blind in their teen years. Child 9, Emilia Eva Sophia born 1845, was also listed as blind. All three girls died as young adults: Johanna in 1850, Christina in 1845, and Emilia in 1866.

When I showed the information to my mother-in-law, we wondered, what could have caused this? She sent a copy of the extensive death record for Johanna to her cousin in Ödeshög, Sweden.

The following is Paul Karlsson's 1980 translation: "As a child she had a healthy body and a sensitive soul, but when she was five and going to begin to read she had weak eyes, (which is) why she never was able to learn the ABC book and the little catechism. In her twelfth year she came down with epilepsy, which

caused damage to her memory and nervous system. The power of comprehension diminished gradually, but the sensitivity increased sometimes. She mourned very much a dead younger sister. A lot of crying weakened her eyes even more. Eight years ago it became increasingly darker for her and she became completely blind. Help was impossible. Once a month the convulsions pained her and laid her in bed for ten days. At the end she lost consciousness." Epilepsy (fallandesot) was listed as the cause of death.

The explanation of the medical problem

Eleanor was working in the medical field and was very concerned. She could not find anything in the medical books. There was nothing here in the family medical history.

I volunteer at a Family History Center on Saturdays. I mentioned it to my co-worker, Kathy Wright. She told me to look up *Batten disease* on the internet. I did. I printed off many pages. When I read them it reminded me of the death record translation. Beginning at age 5 to 10, vision problems and seizures show up in a normal child. Overtime, children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually

they became blind, bedridden, and demented. It is fatal. Death occurs in the late teens or early twenties. Johanna was 24, Stina was 17, and Emilia was 21.

What is this disease?

Batten disease is a disorder of the nervous system. It occurs only when a child inherits two copies of the defective gene, one from each parent. It is uncommon in the United States but more common in Sweden. Kathy knew about it because she helps a family with three children who have the disease.

I do think that George Swanson's three sisters may have had Batten disease. Sometimes the mysteries of genealogy are resolved by talking with others who just might have a suggestion for you.

The author is Jan Sokody Asp 441 Adams St Elgin, IL 60123 E-mail: Jasp441@gmail.com

Editor's note: According to the Swedish Board for Health and Welfare (Socialstyrelsen), 2-3 children are diagnosed every year. There are 5 persons with this illness per each million in the population. There are some 40 people with this illness in the country now.