

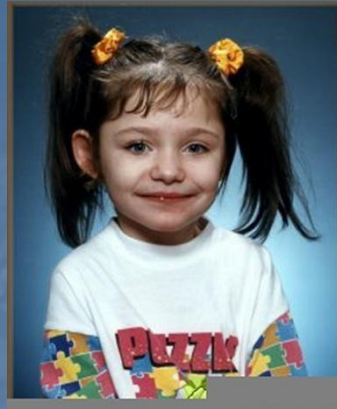
UNDRABÖRN

TUBEROUS SCLEROSIS SYNDROME

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WONDERCHILDREN

TUBEROUS SCLEROSIS SYNDROME

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EFNISYFIRLIT

- HVAD ER TUBEROUS SCLEROSIS?
- EINKENNI
- FYLGISJÚKDÓMAR
- MEÐFERÐ
- FRAMTÍÐARHORFUR
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CONTENTS

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- Symptoms
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- Sources

TUBEROUS SCLEROSIS SYNDROME



HVAÐ ER TUBEROUS SCLEROSIS?

- Tuberos Sclerosis Syndrome (Bourneville Syndrome)
- Tuberos Sclerosis Syndrome(TSC) er erfðasjúkdómur.
- Greiningaraldur

WHAT IS TUBEROUS SCLEROSIS?

- Tuberos Sclerosis is also known as Bourneville syndrome.
- Tuberos Sclerosis Syndrome is caused by a genetic defect of the TSC 1 and TSC 2 genes.
- Most children are diagnosed with TSC between 0-6 years of age.

EINKENNI

- Fæðingarbléttir
- Útbrot
- Húðvöxtur
- Æxli



SYMPTOMS

- Birthmarks
- Severe facial rash
- Excessive skin growth around finger and toenails
- Tumorgrowth on organs or body tissue



FYLGISJÚKDÓMAR

- Flogaveiki
- Hegðunarröskun (ADHD)
- Þroskahömlun (einhverfa)



SECONDARY DISEASES

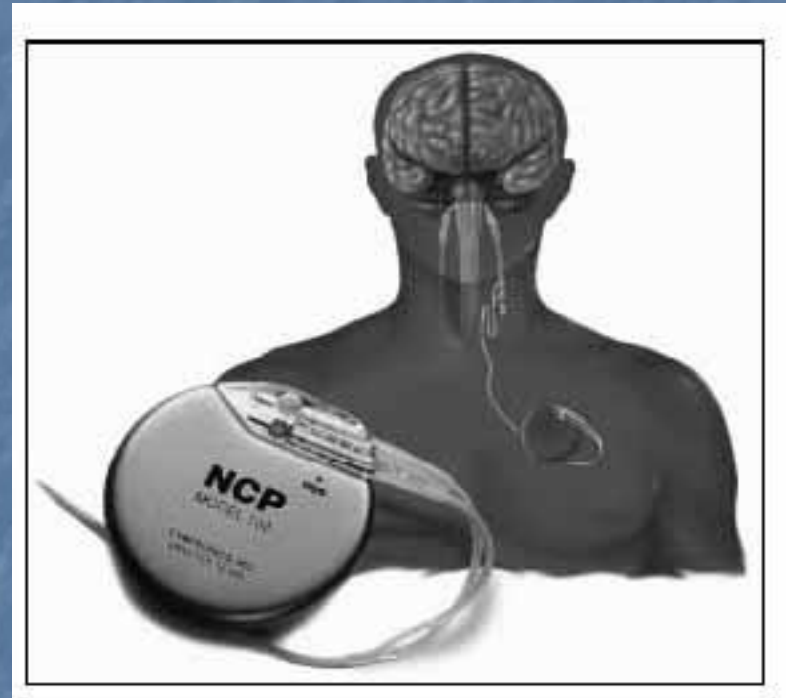
- Epilepsy
- Educational and behaviour disorders (ADHD)
- Mental disorders (autism)

PS. This picture is from a documentary movie called „Sólskínsbarn“ wich means „Child of the Sun“ about a mother and her autistic son.



MEDFERÐ

- Lyfjameðferð
- Lasermeðferð
- Skurðaðgerðir
- Vagus Nerve Stimulator(VNS tæki)
- Matarræði
- ADL/Þroskapjálfun

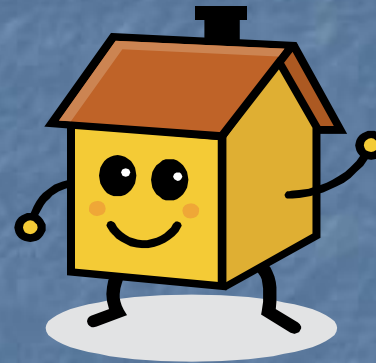


TREATMENT

- Medication
- Laser treatment
- Surgical treatment
- Vagus Nerve Stimulator
- Ketogenic diet
- Physical and/or mental therapy/training

FRAMTÍÐARHORFUR

- Búseta
- Menntun
- Atvinna



FUTURE PERSPECTIVE

- Residence
- Education
- Employment



UNDRABARN "A"

"A" er fimm ára stúlka sem greindist með TSC þegar hún var uppb eins árs. Hún fær 15-30 flog daglega og biður eftir að fá VNS tækið sem mun vonandi minnka flogaköstin og bæta lífsgæðin hennar.



WONDERCHILD "A"

"A" is a five year old girl that was diagnosed with TSC when she was one year old. Today she gets approx. 15-30 seizures daily and is waiting to get the VNS device which will hopefully reduce/prevent seizures and improve her quality of life.



UNDRABARN "M"

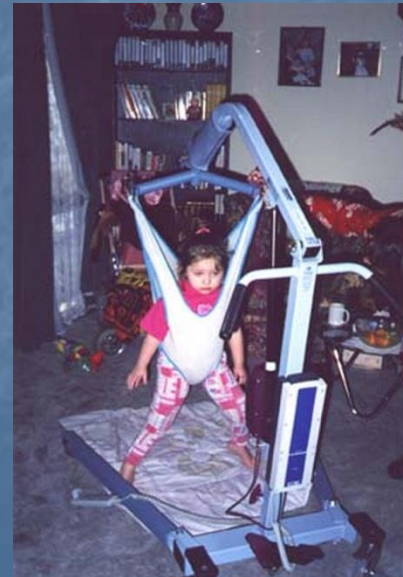
"M" er 15 ára stúlka sem greindist með TSC þegar hún var 9 mánaða gömul og hlaut alvarlega heilaskaða þegar hún var 2,5 ára. Hún er hreyfi og þroskahömluð og byr hjá foreldrum sínum. Hún fer í sérskóla þar sem hún fær viðeigandi meðferð og þjálfun.

Myndirnar fyrir neðan voru teknar áður og eftir að hún veiktist.



WONDERCHILD "M"

"M" is a 15 year old girl that was diagnosed with TSC when she was approx. 9 months old. She suffered severe brain damage when she was 2,5 years old and is both physical and mentally handicapped. She lives with her parents and attends a special school where she gets all therapy and training that she needs.



UNDRABÖRN



WONDERCHILDREN



Í HNOTSKURN

Nú höfum við lýst helstu einkennin og meðferðarúrræði sjúkdómsins og áhrifin hans á líf einstaklinga sem greinist með sjúkdóminn og aðstandendur þeirra.

CONCLUSION

In this presentation we tried to describe the main symptoms, treatments for TSC and how Tuberosus Sclerosis Syndrome changes the life from all the children who are diagnosed with TSC and their family.

Þvi miður er staðreynd að einstaklingar með TSC og aðstandendur þeirra þurfa oft að takast á við forðómum, vanþekkingu, úrræðaleysi og niðurskurð í heilbrigðis og félagsmálakerfinu.

TSC samtök um allan heim gera allt sem þeir geta til að auka þekkingu og skilninginn almennings og fagaðila um TSC, og reyna að bæta stöðu þeirra sem glíma við Tuberosus Sclerosis Syndrome.

Sadly enough it is a fact that TSC patients and their family members not just have to deal with the disease but also prejudices, lack of resources, knowledge and last but not least money for example in the health and social care system.

TSC organisations worldwide try to change this for example by educating the public as well as health and social care personnel, raising research money and encourage TSC patients and their families to share their life experiences with other people. With this they hope to improve the quality of life and future for people with TSC.

HEIMILDIR/SOURCES

- Wikipedia:
www.en.wikipedia.org/wiki/Tuberous_sclerosis
- The Australian Tuberous Sclerosis Society:
www.atss.org.au
- Pritzker School of Medicine-Chicago University:
www.pedclerk.bsd.uchicago.edu/tuberoussclerosis.html
- New Zealand Dermatological Society Inc.:
www.dermnetnz.org/systemic/tuberous-sclerosis.html

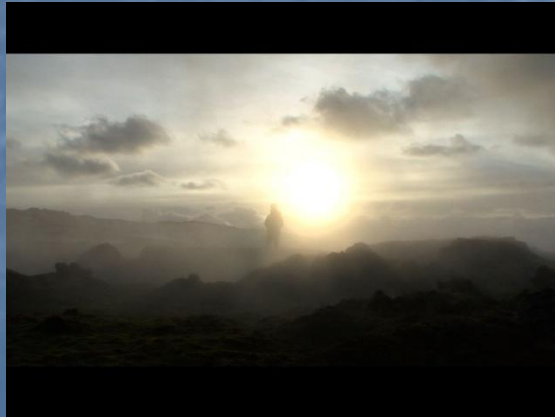
HEIMILDIR/SOURCES(frh)

- American Academy of Ophthalmology:
www.aao.org/theeyeshaveit/congenital/tuberous-sclerosis.cfm
- Epilepsy Foundation of America:
ww.epilepsyfoundation.org/about/treatment/vns/
www.epilepsyfoundation.org/about/treatment/ketogenicdiet/

HEIMILDIR/SOURCES(frh)

- Sólskíndrenginn(heimildarmynd)
www.solskinsdrengur.is/press.html

p.s: Sólskíndrengur is a documentary movie(true story) about a icelandic mother and her autistic son and their battle with his disease(see website: www.solskinsdrengur.is).



HEIMILDIR/SOURCES(frh)

- UNDRABARN "A"

WONDERCHILD "A"



- UNDRABARN "M"

WONDERCHILD "M"

www.melissas.net

