

**THE IMPACT OF A  
DIAGNOSIS:  
A PERSONAL ACCOUNT**

**SASKIA DE KOSTER  
JOOSJE KIST**

**FROM "CEREBRAL PALSY DUE TO LACK OF OXYGEN"  
TO  
GATAD2B ASSOCIATED NEURODEVELOPMENTAL DISORDER  
(GAND)**



# MEETING EACH OTHER



## **HIGH IMPACT**

We are not alone: a new family

Sharing & comparing: what is syndrome ?  
what is personality?

Better understanding of gene function

More respect for our son

Higher status in society: we are RARE

# **PAST**

better understanding of former  
challenges

rewrite history on guilt or blame

# **FUTURE**

More knowledge on what to expect  
vision/speech/metabolism/sleep/scoliosis/osteoporosis

Possibility to anticipate

**COMMUNITY & KNOWLEDGE**

**= POWER !**