

DUTCH REGISTRY 2019

Data of people with CF in the Netherlands

DEMOGRAPHIC DATA

1516
people with CF



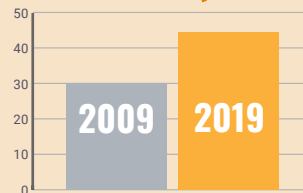
572 **944**

7 CF-CENTRES

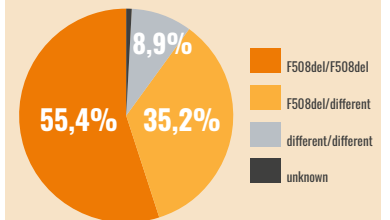


★ **5 LOSSES** ★

median age
at death **44,7** years



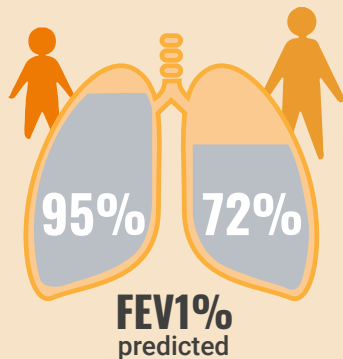
MUTATIONS



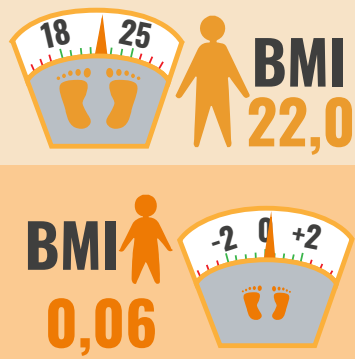
MOST common mutation is **F508del**

SYMPTOMS & CONSEQUENCES

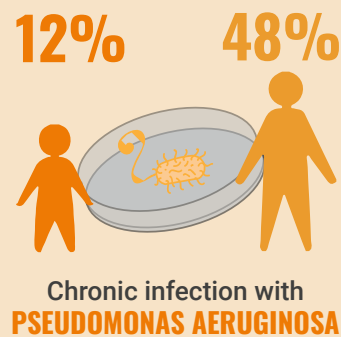
LUNG FUNCTION



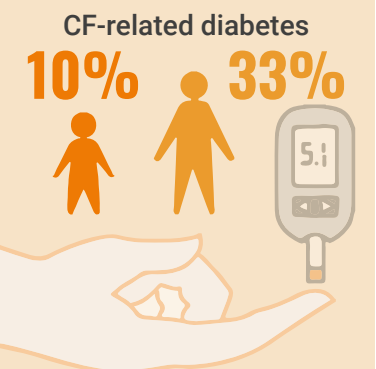
HEIGHT & WEIGHT



BACTERIA

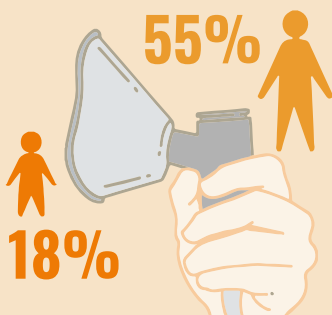


COMPLICATIONS

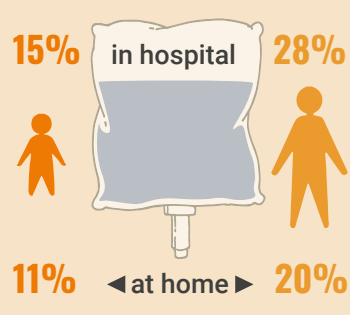


TREATMENTS

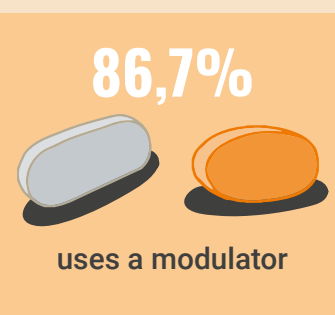
INHALATION ANTIBIOTICS



ANTIBIOTICS via INFUSION



NEW MEDICATION



TRANSPLANTS
lung transplants



WORK & STUDY



NEDERLANDSE
CYSTIC FIBROSIS
STICHTING

Steering group Dutch CF registry

info@ncfs.nl

50-PLUS



DUTCH REGISTRY 2019

128

50 YEARS OF AGE
and older
of which
with confirmed CF-diagnosis

114

51 people are using
INHALED ANTIBIOTICS

62,5% ♂
LUNG FUNCTION
70,2% ♀

24 people are using
SUPPLEMENTAL FEEDING

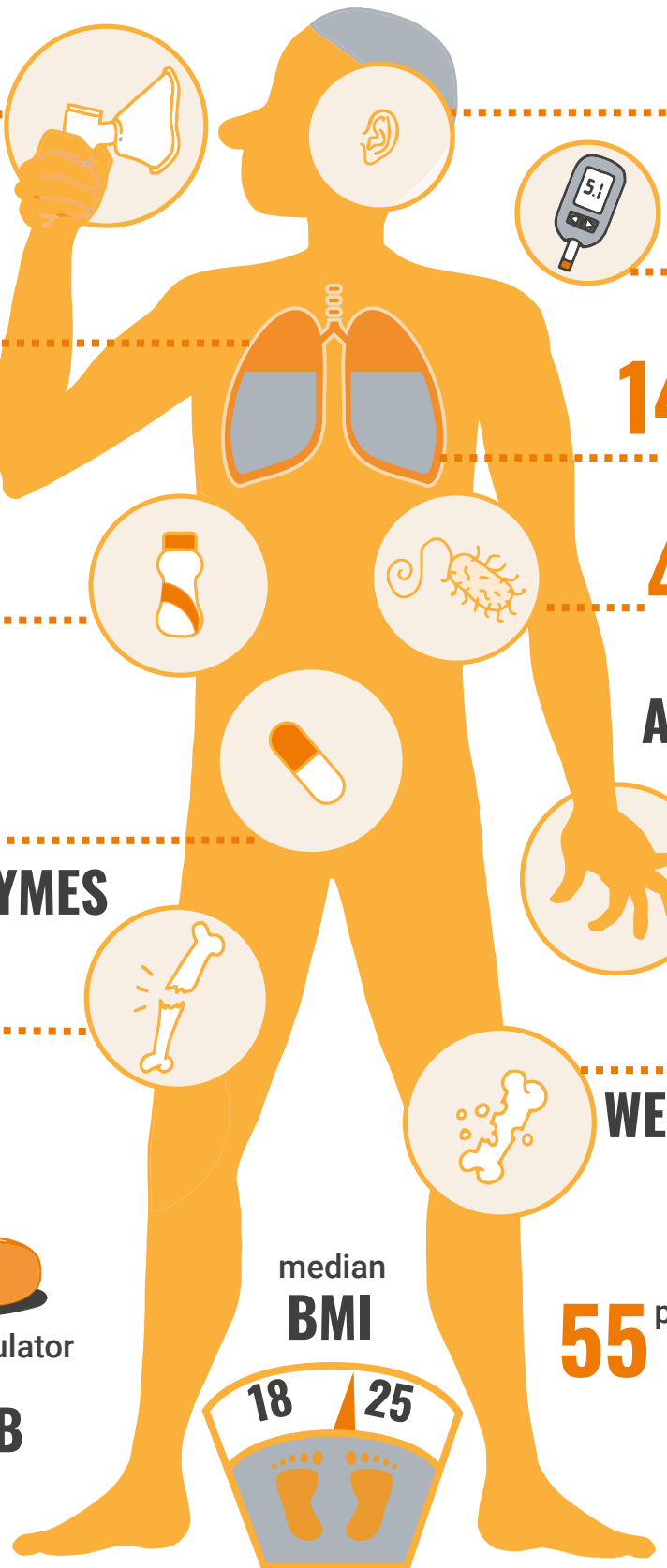
45 people are using
PANCREATIC ENZYMES

11 people ever had a
BONE FRACTURE

NEW MEDICATION

32 people use
a modulator

47 people have a **JOB**



11 people have
HEARING LOSS

25 people have
CF-related
DIABETES

14 people ever underwent a
LUNG TRANSPLANT

43 people have a chronic
PSEUDOMONAS AERUGINOSA infection

16 people have
ARTHRITIS

36 people have
osteopenia
WEAKNESS OF BONES

15 people have
osteoporosis

55 people have been diagnosed
after the age of **18** years

2 people have
PASSED AWAY

22,4 ♀ **♂** **23,6**