

Partnership between sickle cell nurse and families in outpatient clinic

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Nurse (sickle cell disease)

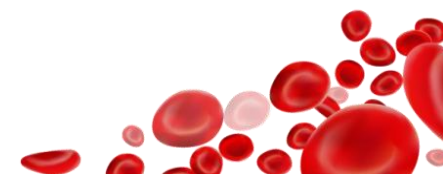
University Children Hospital Queen Fabiola (HUDERF)(Belgium)



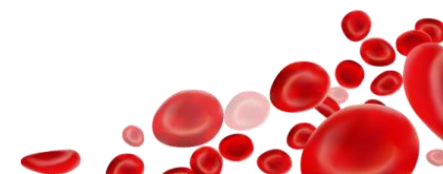
*6th EUROPEAN SYMPOSIUM ON RARE ANAEMIAS
1st Dutch-Belgian meeting for patients and health professionals*

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Disclosures							
Company name	Research support	Employee	Consultant	Stockholder	Speakers bureau	Advisory board	Other
							Nothing



This talk is applicable for:	
Definite	Probable
Sickle cell disease	



Lecture content

1. Sickle cell anemia 's patients in Belgium

2. Partnership in outpatient clinic

Objectives:

Understand what is sickle cell anemia (transmission, prevention, main complications, emergencies situations ...)

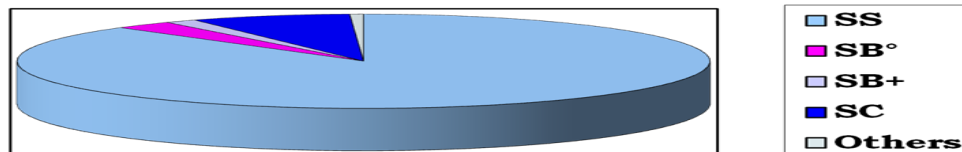
Increase (patient/ family)'s empowerment

3. Cartoon: Sam and sickle cell anemia

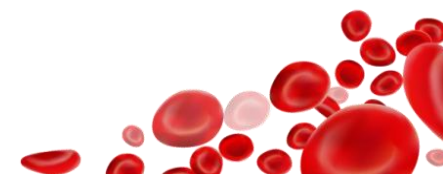


Sickle cell anemia's patients in Belgium

Mostly SS patients



Characteristics	Data
N	469
Sex ♂/ ♀ (%)	223 (47,5) / 246 (52,5)
Genotype SS/Sβ°, (%)	423 (90)
Median age at diagnosis, year (min-max)	0,7 (0-34,6)
Median follow-up, year (min-max)	9,5 (0,1-48,7)
Patients > 18 y	139
Patients from HUDERF	~250



What should patients and families know? The disease

- Sickle cell disease (SCD) is a disorder of the blood caused by an inherited abnormal hemoglobin , S,C, β ...
- SCD is inherited as an autosomal : it touches male and female
- SCD is inherited as recessive condition from both the mother and the father, so that the child has two sickle cell's genes

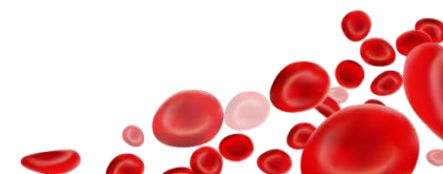
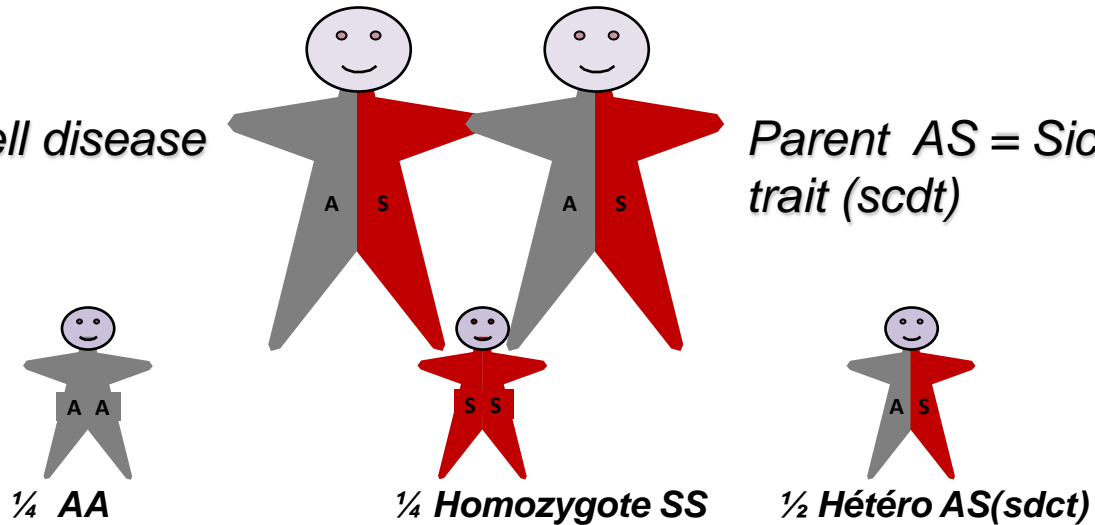


Sickle cell disease's transmission

*Parent AS
trait (scdt)*

Sickle cell disease

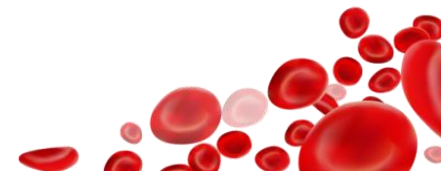
*Parent AS = Sickle cell disease
trait (scdt)*



What do parents and nurse speak about?

To all Neonatal screening parents

- Welcome the family explain the multidisciplinary team : doctors, nurse, psychologist, social worker ...
- Give hope : a child, a sickness, an opportunity of care
- Arise need of follow up :
 - daily medication, vaccination
 - lack of drug
 - regular consultation...
- best cure is preventing complications
- Parents experts and partnership



What do patients, parents and nurse speak about ?

To all patients and parents

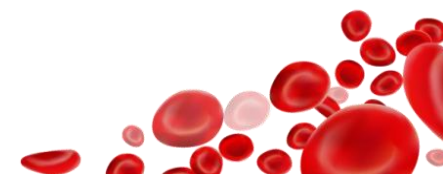
- Living with sickle cell anemia:
 - prevention : hydration, cold, hot time, exercises, school, daily medicine, D vitamin,
 - Current's exams, and the hospital
- How to handle common life's events : school, travel, extra activities, work, adult transition ...



What do patients, parents and nurse speak about ?

To all patients and parents

- Emergencies:
 - Infection : (fever), how to recognize, what to do, when and where to go in the hospital?
 - Anemia : how to recognize, what to do?
 - Acute chest syndrome : how to recognize, what to do?
 - Pain : how to recognize, what to do?



Tools we 've developed

- Patient' s books
- Flyers for the school, for surgery, for people with sickel cell trait...
- Emergency's protocol
- GSM number and registration for patients...
- Cartoon



3. Movie : Sam and sickle cell anemia

- What is sickle cell anemia ?
- When to go to the emergency ?

