

Information document for children

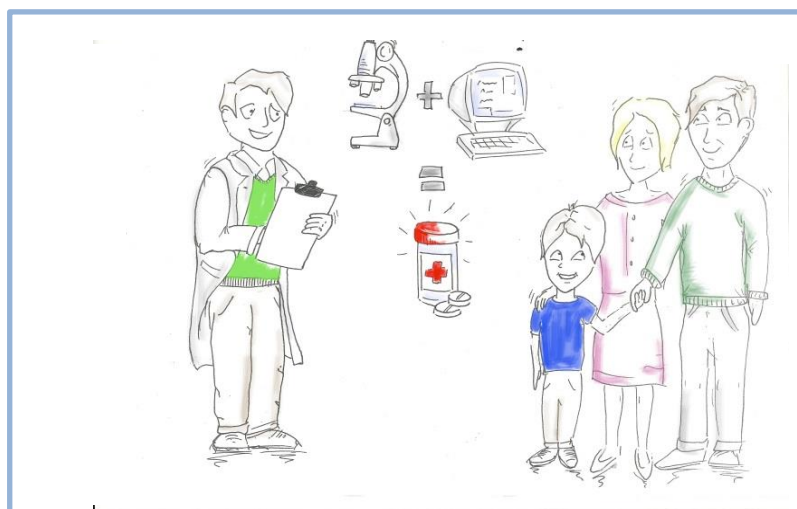
Participation in the European database « “LeukoDB »”

“George and research on leukodystrophy”

1. George has leukodystrophy. This is a rare disease.



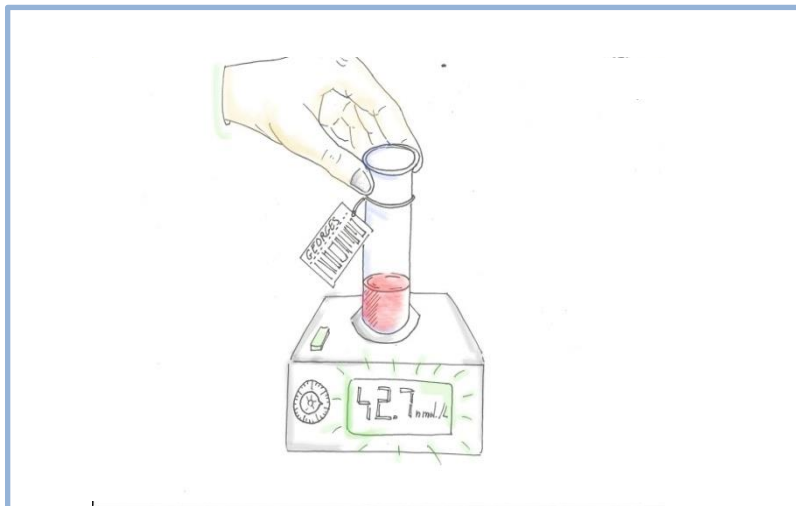
2. The doctor offers George and his parents the chance to be part of a research program to make discoveries about his illness. The aim is to search for new drugs. We do not know yet how long it will take. George and his parents are free to accept or not.



3. For this research, the results of various medical tests (past and future) that George has had will be recorded in a computer.



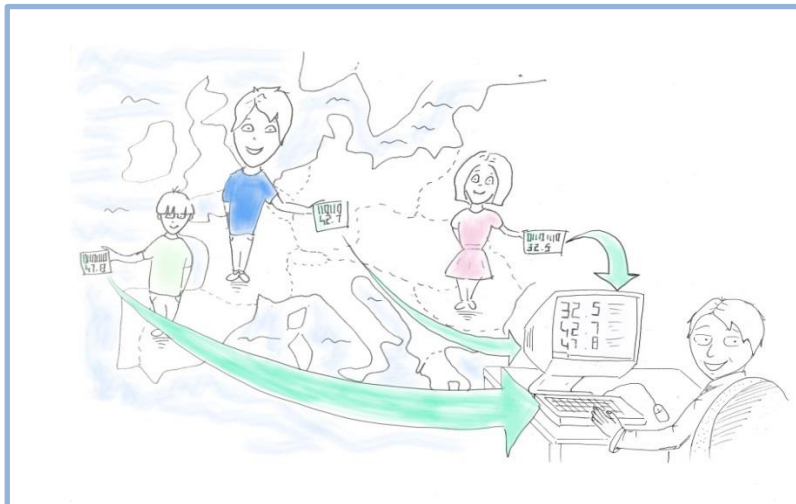
4. These results will be coded so that no-one knows who they belong to.



5. The doctor enters the results and the bar code in the computer.



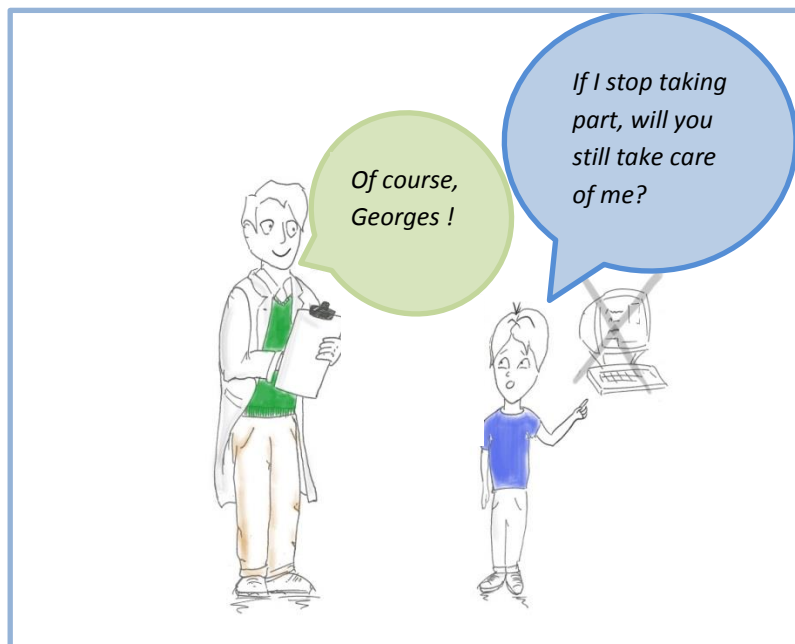
6. With computers, all the researchers and doctors working on leukodystrophy all over Europe will use George's results and those of other children with leukodystrophy to advance research and obtain new drugs sooner.



7. Researchers and doctors work together to find treatments.



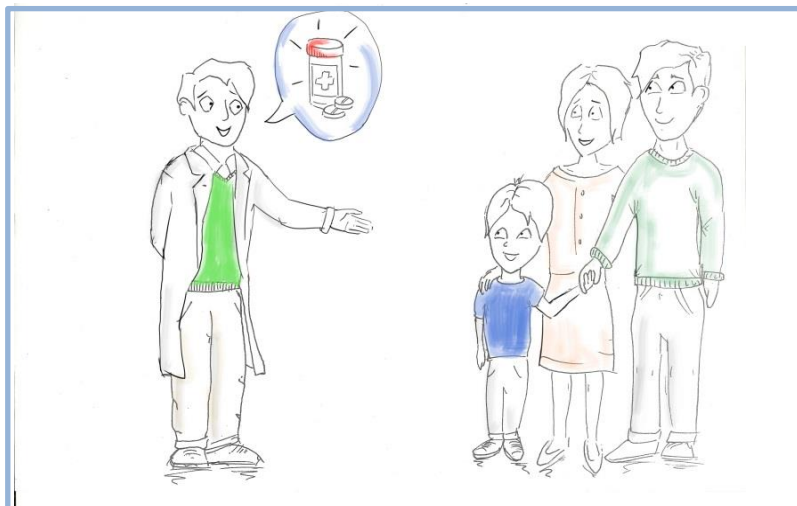
8. George and his parents can decide at any time to stop taking part in this research, but the doctor will still take care of him.



9. George's doctor and the person responsible for recording the results in the computer will always be there to answer his questions and those of his parents.



10. If there are important discoveries about the disease, the doctor will tell George and his parents.



11. Researchers and doctors, other patients and their families thank George and his parents for their help in treating leukodystrophy.

