

## CLINICAL DATA BASE

Gathering blood samples at the bio bank, is as much important as gathering the clinical data analysing the whole medical documentation of your children. We have just received the software where we have to put all this documentation and doctor **Emanuela Ponzi**, a medical researcher, has been hired just to take care of this job.

What I ask you is to urgently send us a copy of the whole medical papers related to your children (on paper or CD), with particular reference to genetic and neurological reports (magnetic resonance, EEG, evaluations...) at the following address:

ASSOCIAZIONE RING 14  
Via Victor Hugo 34  
42123 Reggio Emilia  
ITALY

Upon receiving this material, Dr Ponzi will take care of putting it in our software and will be in touch with you for any further questions. When the software job is completed, each family will receive a password which will enable to access the data of the respective son and print out the full medical card.

All researcher who will need to check our database, will be allowed to do this by requesting us to access it. Our Direction Board will check every request and authorize the access on a case by case basis.

As you know, the next month of October, a very important international workshop will take place, to which 20 within the most celebrated researchers in the world will participate.

More samples we gather in the biobank and more data we add in the database, the bigger will be the reserchers' interest to engage themselves in studying the chromosome 14 syndrome.

I reckon on your cooperation and participation.

In case of any doubt, don't hesitate to contact me.

Sincerely yours,

Stefania Azzali