



1990-2014

Over 20 years vs/ Rett Syndrome

Rse General Assembly, Wien, 15th November 2014



# AIRETT GOALS

Addressing the present and future of individuals with Rett syndrome

**means**

- To stimulate and support research into genetic, clinical or rehabilitation.
- Activate Centers of reference for taking in charge of the clinical, cognitive and motor aspects.
- Be supportive to families.



## The Research is the present

**Important to know to do research**

Therefore, it is important to have referral centers



Professionals provide with experience and competence

- correct assumption




- stimulus to Research



# The research is also hope and future

## Start up of Airett Research Team with the following objectives



500 mila euro????  
come ottimizzare  
la ricerca???

Will do research in a new way with the basic sharing of the results, the models tested , working on joint projects to make rapid progress toward a cure . *Research Team dealing simultaneously with all three mutations ( MECP2 , CDKL5 and FOXP1 ) that cause Rett .*

The Consortium is formed by :

- IRCCS- Istituto di Ricerche Farmacologiche “Mario Negri” di Milano
- Istituto Superiore di Sanità di Roma
- Istituto di Neuroscienze di Pisa
- IRCCS- Istituto Auxologico di Milano
- Dipartimento di Neuroscienze dell’ Università di Torino
- Istituto di Genetica e Biofisica del CNR di Napoli
- Università degli Studi di Siena

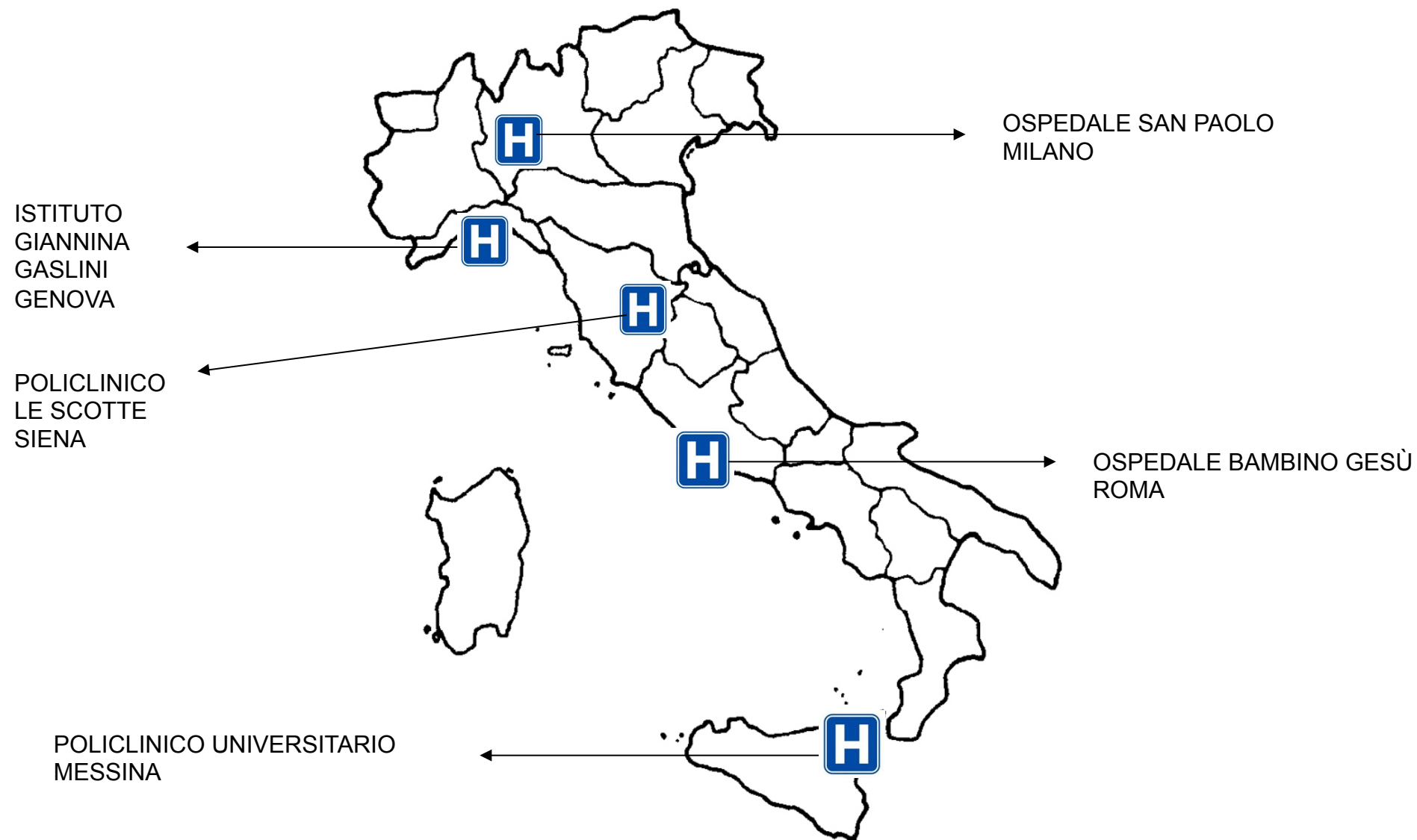


# SPECIFIC AIRETT GOAL

IDENTIFICATION AND PROMOTION OF CENTRES  
OF EXCELLENCE IN THE TREATMENT OF  
NEUROLOGICAL AND NON - SPECIFIC ISSUES IN  
RETT SYNDROME .



*FIVE CENTRES TO*  
*COOPERATE WITH AIRETT*  
*FOR TAKING CHARGE OF*  
*RETT SYNDROME*





## *OBJECTIVES OF CENTRES*

- HAVE A COMMON PROTOCOL FOR TAKING CHARGE
- WORKING IN THE CENTRE IN MULTIDISCIPLINARY TEAM
- NETWORKING WITH OTHER CENTRES
- LOCATE IN ANY CENTRE AN AREA OF EXPERTISE
- PROMOTION OF RESEARCH ON RETT SYNDROME
- PROJECT " PASSPORT CLINIC "





## ORGANIZATION OF CENTRES

ONE REFERENCE DOCTOR FOR EACH CENTRE WITH THE TASK OF :

- PROGRAM DAY HOSPITAL
- LOCATE IN HOSPITAL PROFESSIONALS REFERENCE ;
- FOLLOW THE PATIENTS DURING DH ;
- FOLLOW THE TIMING OF DELIVERY OUTCOMES DH RESULTS ;
- UPDATE LIBRARY RETT ;
- COLLABORATE ACTIVITY ' CLINICAL SCIENCE ;
- PROMOTE THE PROGRESS OF PDTA ;
- PROMOTING COOPERATION NETWORK OF CENTRES RETT ;
- PROMOTING THE SUPPORT FAMILIES ;
- ORGANIZE AND MANAGE THE OPENING OF " PASSPORT CLINIC "



## AIRETT COMMITMENT



FINANCIAL SUPPORT TO ANY MEDICAL CENTER TO ENSURE THE REFERENCE FOR



ACTIVATION OF TELEPHONE LINE DEDICATED AT EACH CENTRE ;



IDENTIFICATION OF A FACILITATOR FOR THE DEVELOPMENT OF COMMUNICATION BETWEEN THE DIFFERENT CENTRES AND INFORMATION NEEDS ASSISTANCE TO FAMILIES ON COMPLEX



## CONCLUSIONS

CENTRES OF REFERENCE FOR RTT ARE AN EXCELLENT OPPORTUNITY ' FOR FAMILIES WITH RETT GIRLS

START UP REQUIRED TIME, COMMITMENT AND DEDICATION

IT IS NECESSARY TO CONTINUE THE COLLABORATION OF ALL , FAMILY , HEALTH ..... .



ESSENTIAL TO KNOW THAT :

EVERY START UP NEED IT RUNNING ..... *TAKES PATIENCE*



WHO IS WORKING CAN MAKE MISTAKES.....*NEED COMPREHENSOR*



CRITICAL AND OBSERVATIONS MADE WITH ONE GOAL TO IMPROVE AND GROW

*WE WANT HONESTY*



REQUIREMENTS OF THE GIRLS AND THE PAIN OF FAMILIES ARE INVOLVED WITH CAUTION  
AND CARE ... .. *WE WANT TO HUMANITY ' AND DEDICATION*

