

INFORMATIVE REPORT AND CONSENT TO PERSONAL DATA TREATMENT

- section “histories of our children” – www.ring14.org

The undersigned :

Parent of:

E-mail address:

(optional, will be used to inform you about the Association’s initiatives)

Informed and aware that:

In the site section given up to “histories of our children” are presented information even of sensitive nature (data about health), concerning some cases of ring 14 syndrome or of other chromosomal aberrations tied to 14 chromosome (deletions, translocations, duplications).

Information is directly and spontaneously provided by concerned families.

Sensitive kind data, with specific reference to those about health (possible images included) are protected and made accessible upon certification (userID and password) only for the subjects who make precise request to the Association and after proper registration.

Therefore data are not spread on line to all internet users, in observance of the decree with the force of law No. 196/03. On the contrary, upon explicit consent, the e-mail address will be published on the site www.ring14.org and therefore made available to all interested internet users.

To send personal data to ring 14 Association, for the aims and within the limits indicated above, it is necessary to subscribe this informative form and consent and to send it via fax to the No. +39 0532 324835 or to send it via mail by the office of Ring 14 Association via Victor Hugo 34 42100 Reggio Emilia Italy.

Only after this sending it is possible to fill up the on line questionnaire and however to provide information to the Association.

In default of the subscription and sending of above –named form, Ring 14 Association will not be able to use personal data.

The so collected data are inserted either on a computerized database, or kept in paper archives by the operating office of the Association to which only the members of the Steering Committee of the Association and of the Scientific Committee, and specific responsible of Ring 14 as well, can accede.

The International Ring 14 Association for the research on rare neurogenetic illnesses – Onlus (non profit making organization) holder of the treatment , guarantees the right to obtain in every moment a confirmation of the data existence, to ask a correction, the updating or the cancellation, to be opposed to all or to a part of the treatment, the exercise of any other right provided for by the article 7 (decree with the force of law 196/03). For this aim it is possible to apply to: International Ring 14 Association for the research on rare neurogenetic illnesses- Onlus (non profit making organization) via Victor Hugo 34 42100 Reggio Emilia Italy Phone +39 0522 322607 Fax +39 0522 322607.

Expressly consent to the treatment of the personal conferred data, for the aims and within the limits indicated above.

(name, surname and signature)

Expressly consent to the publication of its own e-mail on the site www.ring14.org

(name, surname and signature)