



European Cytogeneticists Association
Register of Unbalanced Chromosome Aberrations
Department of Human Genetics
Radboud University Nijmegen Medical Centre
P.O. Box 9101, 6500 HB Nijmegen, the Netherlands
Tel: +31 (0) 24 361 4105, Fax: +31 (0) 24 366 8751
E-mail: info@ecaruca.net



Information letter

Dear colleague,

Hereby your participation in the European Cytogeneticists Association Register of Unbalanced Chromosome Aberrations (ECARUCA) is requested concerning one of your patients.

The cytogenetic data of the patient below have been submitted by

.....
and he/she reported you as the physician for the accompanying clinical data.

Patient data

Date of birth:

Gender: MALE / FEMALE / AMBIGUOUS / UNKNOWN (please circle your choice)

Karyotype:

ECARUCA is a database that collects and provides cytogenetic and clinical information on rare chromosomal disorders. The project was initiated by the board of the European Cytogeneticists Association (ECA) and is supported by the European Union. The main goals of ECARUCA are to improve the clinical knowledge of rare chromosome disorders and to encourage cooperation between the European (cyto) genetic centres on their study of rare chromosome disorders.

ECARUCA is available on the Internet and is free of charge. The site consists of an open part, containing general information about the project, patient organisations and interesting links. The other section is password protected and only accessible for account holders. An account can be requested by professionals working on rare chromosomal aberrations and by parents of a child who's data is collected in the ECARUCA register. Parents only have access to the information of their own child. The restricted pages contain details on karyotype, medical data and photographs. All patient information is provided anonymously.

For more information about ECARUCA please visit our web site: www.ecaruca.net

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Anneke van Silfhout, MD (Clinical Database Manager)
Nicole de Leeuw, PhD (Daily management ECARUCA)

Rita Dirks (Administrative Assistant)
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Information Letter (continued)

We would highly appreciate if you could bring the ECARUCA project under the attention of your patient and family and ask permission to submit medical data and possible photographs for ECARUCA. In case your patient is willing to cooperate we kindly request you to fill out the *"Declaration of Permission"* form, which you have received in this mailing (if not, please contact ECARUCA via email or the address below). Clinical data can be entered by login in to the member section of the ECARUCA website and clicking the link "Submit clinical information". Your username and password are included in this mailing. Instructions for using the interface for submitting clinical information are available on the Manuals page of our website.

Please fill in the requested information as completely as possible. The signed *"Declaration of permission"* must be kept in the record of the patient, in order to guarantee privacy.

If you have any questions regarding the ECARUCA project, please do not hesitate to contact us.

ECARUCA (for the attention of A. van Silfhout)
Department of Human Genetics, 849
Radboud University Nijmegen Medical Centre
P. O. Box 9101
6500 HB Nijmegen
The Netherlands

Kind regards,

ECARUCA Project Management Board

www.ecaruca.net

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