

## **INFORMATION ON RARE GENETIC RENAL DISEASES BY AIRG**

Two booklets on two genetic renal diseases have been published recently with the financial support of AIRG-Suisse:

- a) Cystinurie (2014)
- b) Hyperoxaluries primaires (2016)

500 copies of each booklet have been printed. They have been distributed to the different sections of AIRG in France, Belgium and Switzerland.

For Switzerland, 100 copies of the booklet on Cystinurie have been received, and a first batch of 60 copies of the booklet on Hyperoxaluries primaires.

The brochures are presented each year to concerned people on different events, as for instance the celebration day of the 10th anniversary of AIRG-Suisse (25.10.2014), on the yearly Kidney Day (2<sup>nd</sup> Thursday in March), and on the Annual Congress of the Swiss Society of Nephrology. The booklet is sold to professionals (doctors, nurses, social workers) and given to affected members and their families.

The financial support of the Eagle Foundation has been a key factor for the printing of two leaflets :

1. Cystinurie : 3000.- out of a total cost of 12'076.80 Euros have been paid by the Eagle Foundation.
2. Hyperoxaluries primaires : the total cost of 12'327.60 Euros has been taken in charge by the Eagle Foundation.

The two booklets, written by well known experts, are very much appreciated by both patients and professionals. Following their presentation to members of the Swiss Society of Nephrology, the decision has been taken to progressively translate in German the available booklets. A financial support has been found for the publication in German of the brochure on Adult Polycystic Kidney Disease.

As initially suggested by Mrs Bhavna Dziurzinski, the next, and some of the previous brochures will be available online. The board of AIRG thinks however that the booklets should still be released as paper prints.

The AIRG-Suisse, AIRG-France and AIRG-Belgique are deeply grateful to the Eagle Foundation for making possible the rapid release of booklets on two major rare hereditary renal diseases.

With all good wishes,

Dr Jean-Pierre Guignard  
President of the Scientific Committee of AIRG-Suisse

Alain Essade, Treasurer of AIRG-Suisse