

# REiNS EUPATI Educational Document

September 2018

The REiNS Patient Representative education sub-committee is pleased to provide the first recommended educational document for REiNS patient representatives to review. Our team, which included clinicians and current patient representatives, reviewed what resources are currently available for education which would be relevant for a REiNS member. After reviewing multiple different options, we settled on using materials from an educational program created by a European organization named, European Patients' Academy (EUPATI) (<https://www.eupati.eu/what-is-eupati/>). While the full EUPATI patient training course is intensive and requires over 200 hours of participant time, we have tried to select the materials most relevant for our group. The intent is to provide educational content which will enable patient representatives to participate actively in the overall REiNS goal of providing directions for current and future NF research. We have created a "core" document which contains these materials.

Of note, because these lessons were made for a European audience, you will find many references to European organizations, documentation, etc. However, the principles of clinical trial design, research ethics and the other topics included in this document apply equally well to trials performed in the United States. We hope this will not be a distraction to you. In the future, we will provide a second document of "extra readings" from the EUPATI website that you might wish to review. We know even with the "extra readings", our selected materials are not comprehensive, and anyone who is interested in more information can enroll in the full EUPATI course at the link provided above.

We welcome any feedback! Please let us know if there are questions on the content or suggestions for additional topics. We are also very open to input from anyone with website/graphic design expertise who might be able to help us make the lessons a little more user friendly than the current document format (and less likely to be a cure for insomnia!).

Many thanks to the entire patient representative education team, and in particular to Claas Rohl, for helping us utilize the EUPATI materials and getting permission for us to share them on our REiNS website, and to Dale Berg, for sorting through and organizing the selected EUPATI lessons.