Reviewer’s report

Title: Renal manifestations of Tuberous Sclerosis Complex: patients' and parents' knowledge and routines for renal follow-up - A questionnaire study

Version: 0 Date: 14 Oct 2017

Reviewer: Darcy A. Krueger

Reviewer’s report:

The manuscript is straightforward and easy to follow. The focus of the manuscript, patient knowledge and surveillance patterns for renal angiomyolipoma is relevant to optimal management of this common clinical aspect of tuberous sclerosis. I only have some minor concerns for the authors to address:

1) Methods report only informed consent was obtained for Norwegian participants. Either report the same practice was followed for French participants or include a statement in the methodology that requirement for informed consent was waived by the ethics board or regulatory body providing oversight for the study in France.

2) Prior to international consensus recommendations published in 2013 in which renal surveillance imaging was recommended to be done every 1-3 years, recommendation for surveillance imaging in TSC had not been emphasized in published literature for the most part since 1998-1999. As this study was conducted in France prior to 2013 and the bulk of Norway surveys done afterward, could this have contributed to the lower utilization of surveillance imaging in France compared to Norway (in addition to differences in health care systems, etc.)?

3) 2nd to last paragraph on page 10 in results section, has obvious typo. At first I thought on line 37 a simple omission of "three" before years was the problem. But then in continuing to discuss the details of the observation that some patients receive no imaging at all, adding up the different subgroups indicates that the authors are describing those without any imaging (N=24) rather than those who were not getting imaging at least every 3 years but at least had some imaging in the past (N=76). This needs to be fixed/clarified.

4) In the discussion, the authors stress the importance for clinicians and other sources of information to parents/patients provide education/awareness of angiomyolipoma and associated bleeding risk at least by age 15y (and thereafter). It would be helpful and important for the current discussion regarding angiomyolipoma bleeding risk in TSC therefore to include in addition to age risk (that they do discuss) what is known about risk of bleeding overall from prior epidemiology/natural history studies as well as the current literature (albeit limited) that suggest that angiomyolipoma size >4cm (Ewalt 1998) is also an important risk factor.
Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Yes

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.

Unable to assess

Are the conclusions drawn adequately supported by the data shown?
If not, please explain in your comments to the authors.

Yes

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

I am able to assess the statistics

Quality of written English
Please indicate the quality of language in the manuscript:

Acceptable

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I have in the past five years received reimbursements and research support from Novartis Pharmaceuticals, which markets the drug everolimus for treatment of angiomyolipoma in adult patients with TSC.

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