

National Reye's Syndrome Foundation Advisory Committee

The *first meeting* of the National Reye's Syndrome Foundation Advisory Committee was held at the London office of the Royal College of Paediatrics and Child Health on Tuesday 8 October 2013.

Among the matters considered were:-

- Terms of Reference – the group considered a number of aspects, including membership. A number of changes were suggested.
- Decreased consciousness guideline - various matters were discussed including the ownership of the intellectual property.
- Legacy fund
- Financial statement
- Criteria for future applications and communicating funding opportunities
- Reye's/UK website – the websites' passwords came up for discussion.
- Past records

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The *second meeting* of the National Reye's Syndrome Foundation Advisory Committee was held at The International Conference Centre, Birmingham on Thursday 28 April 2015 during the Royal College of Paediatrics and Child Health annual conference.

Among the matters considered were:-

- Decreased consciousness guideline – the guideline had been officially launched at the College annual conference the previous day. It was noted that attendance at the Conference guideline session was good, and that a number of positive comments and discussions took place.

The guideline can be found on the RCPCH webpage -
<https://www.rcpch.ac.uk/resources/management-children-young-people-acute-decrease-conscious-level-clinical-guideline>

- Financing for the updating of the guideline
- Legacy potential ideas for further research
- Financial statement

- Reye's/UK website – recent developments were noted. It was queried whether anyone within the College would be able to look over the medical content of the website.
- Foundation's past records - the visit of the archivist to the hon. administrators' home to review the content of the records was noted.
- Nominated deputy - for the hon. administrator was agreed.
- UK Expanded Newborn screening- this project has now ended. Two Reye-like disorders had been accepted for screening viz Maple Syrup Urine Disease (MSUD) and Isovaleric Acidaemia (IVA).

The *third meeting* of the National Reye's Syndrome Foundation Advisory Committee was held at the London office of the Royal College of Paediatrics and Child Health on Thursday 14 July, 2016.

Among the matters discussed were:-

- Decreased consciousness guideline and general update – the group was updated on the current situation and algorithm amendment. There were still a number of education training materials and leaflets to be produced. With regard to the revision of the guideline, this was *agreed* to be a priority. The decreased consciousness guideline had been included on the list of guidelines in the rolling programme.
- Research – a number of suggestions were considered, together with the mode of funding.
- Publications - members of the previous decreased consciousness project board had been contacted with two potential ideas for publication viz:-
 - Guideline review article, and an
 - Education paper– a mixed methods approach to review the evidence in the development of a clinical guideline.

The group thought these publications were a great idea.

- Financial statement
- Reye's/UK website – a number of matters were discussed. It was *agreed* there should be liaison with the IS Team and the website project group to consider how the management of the Foundation website could be transferred across to the College.

The *fourth meeting* of the National Reye's Syndrome Foundation Advisory Committee was held at the London office of the Royal College of Paediatrics and Child Health (RCPCH) on Monday 5 November 2018

Among the matters considered were:-

- Reye's/UK website – at an earlier meeting in the day a member of the College digital and creative media team put forward three options with regard to the website migration. A summary of the discussion and an estimate of cost for each option is to be prepared. It was reiterated that the aim of the migration is to try to get more traffic through the Reye's website.
- Decreased consciousness guideline and general update – a number of clinical matters were discussed. The guideline is to be reviewed to see if there is a need to do a partial or complete update of the guideline. The time lines will need to be refreshed and agreed.

Concerning the use of the guideline, it was noted that parts of it are used in various ways, as it currently forms part of the eLearning that is recommended before certain courses. It is also referred to in national guidelines. It was mentioned that no guideline is ever used in its entirety, but the important point is that it is known about and used in part or as a framework.

It was noted that when the update is complete the guideline can be promoted further. Re-launching the website will also help the College to sign post the guideline to a greater degree.

- Publications – a number of matters appertaining to the decreased consciousness guideline were discussed.
- Financial statement