**MDS Membership Survey feedback – Response of the Task Force**

Thank you to those who provided thoughtful comments. Many improvements to the paper were made as a result. We would like to share our response to specific suggestions where explanation may be helpful.

1. “I would suggest considering a list of possible but unlikely manifestations of movement disorders with some genes at least as a supplement to guide our clinical thinking.”

**Response: As a supplement to our core lists we are developing an on line tool that will like phenotypes entered by a clinician to genotypes and this will include less likely possibilities with probabilities associated with each.**

1. “I think the only viable solution in this era will be to use a systematic name that has been assigned by Hugo and to create databases (searchable online and with mobile devices) arranged by phenotype or genotype.”

**Response: We absolutely agree and are developing such a bidirectional tool (see #1 above). We see our lists as a cleanup of errors in the current system while we transition to a method that can handle the vast array of knowledge that will accumulate over the coming years (i.e. a searchable electronic resource).**

1. ”The use of the prefix NBIA is not intuitive as it does not follow the same phenomenological criteria as for the other prefixes. Would not use it!”

**Response: The point is well taken however we decided to keep it for now as it has become a widely adopted term by clinicians presumably because the characteristic imaging abnormalities are such a useful diagnostic clue. We will be careful to always accompany it, where justified, with a phenomenological prefix.**

1. The following disorders are missing:
   1. FXTAS – **This disorder will be included as we expand the ataxia tables to include x-linked and recessively inherited types.**
   2. Inherited myoclonus – **We will be working on these disorders**
   3. Tremor – **There are currently no confirmed essential tremor genes. It would be quite reasonable to consider FXTAS as a genetically determined tremor disorder, likely with a combined tremor/ataxia prefix**. This will become relevant as we tackle ataxias other than the autosomal dominant ones.
   4. NARP – **We have included for now the autosomal dominant ataxias and others will be considered as part of future work**
   5. Many combined (aka secondary) dystonias are missing – **Secondary dystonias correspond to ‘complex’ dystonias in the new nomenclature. We have tried to include all disorders where dystonia is a prominent and consistent feature – the absence of some entities may relate to not meeting this requirement. We would be prepared to assess specific suggestions from the membership.**
   6. ANO3 – **independent verification is not yet published**
   7. EIF4G1 – **this is as yet unconfirmed as a cause of parkinsonism and also found in controls**
   8. SCARB2 – **this will be addressed as myoclonic disorders are added to the list.**
   9. KCNMA1 – **We could not find references to mutations in this gene causing a movement disorder predominant phenotype. We would need more guidance to further consider.**
   10. KCNC1 – **We will be reviewing this as we tackle the myoclonic disorders**
2. I would assign the following disorders to a different list
   1. Pediatrics and orphan disorders – **we opted to integrate them to avoid any perception of considering them of lesser importance.**
   2. ATP13A2 should also be designated an NBIA – **Brain Iron on imaging has not been a consistent feature of this disorder.**
   3. DYT11 should be a myoclonic disorder – **this can be considered for a combined prefix when we develop a list of genetically determined myoclonus**
   4. Restless legs –At the present time there are no causative genes known for RLS – although risk variants have been identified.
3. “It would be wonderful to have an asterisk by the genes that are commercially available or all are available…having this defined.”

**Response: All are currently commercially available. We will mention this in the manuscript.**

1. “It is unclear to me how the inborn errors of metabolism with a predominant movement disorder were selected given that this group includes many others for example lysosomal storage diseases, other mitochondriopathies…”

**Response: All such groups of inborn errors of metabolism were considered for inclusion; the ones that were chosen are those that after a review of the literature could be considered to be predominant (and consistent) movement disorders. Many disorders were excluded on the basis of not having movement disorder as the predominant clinical feature.**

1. “I am not entirely sure if parkinsonism has indeed been reported in HSP-ZFYVE26 – please provide a reference.” -
2. **Response: Schicks et al. Movement Disorders 2015, DOI: 10.1002/mds.** “Along with the classification system an app should be floated simultaneously to be able to keep up with the classification.”

**Response: This is a good idea. Our online tool under development (see #1 above) should meet this need.**

1. “Try to set up a joint publication between Movement Disorders and a fine genetics journal…”

**Response: We are approaching the editor of Movement Disorders to see if this may be acceptable. We all agreed this was a good idea.**

1. “I would include C9orf72 disease”

**Response: This was not felt to be a predominant movement disorder.**

1. SCA should be integrated in iPD genes and MSA genes. More collaboration from Asian specialists is needed.

**Response: We have acknowledged the issue of ethnic-specific variation in phenotypes and where well established variations exist have added this in the phenotypic notes.**

1. “The inclusion of metabolic disorders in the list can be a problem…it can encourage genetic or metabolic tests for such conditions in patients with no possibility of having these diseases. …”

**Response: We hope that the phenotypic notes will provide enough guidance (e.g. age of onset, developmental delay…) to avoid creating too many such problems.**

1. Dopa-responsive dystonia is a very distinct disorder with partial enzyme deficiency and have a mild disease course if they are appropriately treated, thus it should be separately designated as DRD-GCH1…”

**Response: Dystonia is a central feature of dopa-responsive dystonia nonetheless, and there are mild cases of other dystonic disorders as well. It was felt that most clinicians would expect to find it under the dystonic disorders.**

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