



ACHDNC Listening Session Update

Family / Representative Organization Group

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On the nomination process, families ...

- ... feel they are the right ones to submit the nomination packet, but do not have the resources including money, person power, and statistical expertise.
- ... are seeking partnership, collaboration and efficiency regarding data collection and statistics. Could we have a shared data collection platform rather than considering nominations one condition at a time?
- ... would like to be involved earlier and throughout the process, not just given a chance for public comment the day before the vote.

On the evidence review process, families ...

- ... feel that the risk of uncertainty and potential harm is overly valued by the committee: “it should be subject to the same evidence-review as potential benefits”
- ... want all the information that is available, even if it is uncertain, because they believe parents should have the right to make decisions about how to proceed with potential treatment options, not the committee.
- ... want a seat at the table ... Can there be more than one parent on the committee?

Additional considerations

- Cost is hard to assess: public health cost versus parents' costs? Parents want to be able to make these decisions themselves.
- The benefit of saving a life by getting a true positive sooner is SO MUCH GREATER and cannot even be compared to the risk of a false positive.
- Families suggest we start screening for conditions to generate data – then we can evaluate the conditions and see which are appropriate for NBS.