



2017 Family Conference Family Vision Breakout Summary

At the August 12, 2017 Family Conference, a total of 51 family members, broke out into 5 discussion groups. They reviewed the [Draft NNPDF Vision for the Future](#) and were asked two questions. Below are the questions and the summary of the feedback.

QUESTION 1:

Do you agree a national central patient support organization as outlined in this document is important to the NPD community? If yes, why? If no, why?

GROUP	AGREE	COMMENTS
1	Yes	<ul style="list-style-type: none"> • Need for resources for both families and physicians • A few members thought there should be one international foundation • Family support handled by someone who understands it • Newly diagnosed families need a resource to contact • Families need supportive services – getting insurance coverage, equipment, etc.
2	Yes	<ul style="list-style-type: none"> • Unite disease groups • Families shouldn't feel obligated to support fundraising for NNPDF • A few members thought there should be one international foundation
3	Yes	<ul style="list-style-type: none"> • One suggestion for peer-to-peer support and connections • Suggestion that NNPDF search engine be optimized so it becomes the first point of contact for NPD families • Resources organized by disease type, ages and local needs • Advertise research and other 501c3s • NNPDF should reach out to families but board member explained private charity cannot do this because HIPPA regulations
4	Yes	<ul style="list-style-type: none"> • Professionally trained Executive Director important to lead group • Quota on board for representation on each disease group • Patient registry important • Vision needs to be established first, then bylaws
5	Yes	<ul style="list-style-type: none"> • Central organization serves a unique and crucial role and cannot do what other partners/family foundations can do • Organization needs to be professionally run • Transparency is important to the vision

QUESTION 2:

What parts of the vision outline do you agree with and why? What parts do you disagree with and why? What parts of the outline would you change and why?

GROUP	AGREE	COMMENTS
1	Yes	<ul style="list-style-type: none">• Need to be more collaborative otherwise there will be more splintering of groups• Encourage exchange of ideas between families• One member expressed dissatisfaction over several issues such as the feeling that families do more than the foundations and that families have to wait to get questions collected and answered after conference
2	Yes	<ul style="list-style-type: none">• Yes hire a social worker• Hire a dedicated fundraiser• Include bereavement services• Increase disease awareness on social media• Desire to know the roles being funded and how they are helping us
3	Yes	<ul style="list-style-type: none">• NNPDF should focus on patient support and not take on too much with research• Confusion over who to guide support to, because there needs to be research and family support• Important to collaborate effectively with FDA• Families want transparency on where funds are used• NNPDF gather research information in layman's terms• A universal information sheet is needed for physicians• Resources are needed for new families
4	Yes	<ul style="list-style-type: none">• Suggestion to outreach to clinicians to facilitate diagnosis• Suggestion for clinical advisory• Provide proactive clinical outreach• Closed Facebook group• Provide information to navigate therapeutic choices• One idea for clinical/translational advisory board to provide vetted information to families and answer questions• Tweak vision statement to include families no matter where they are in the journey• Host monthly webinars
5	Yes	<ul style="list-style-type: none">• Some believed that the Executive Director needs to change periodically and others disagreed• Add to vision: All families welcome and encouraged• Provide proactive clinical outreach• Closed Facebook group