



Vision of Hope  
Meeting the Needs of Today

## NNPDF 2017 Family Conference Summary of Reinvention Panel Feedback

On August 12, 2017, the Ad Hoc Transition Committee and Board hosted a panel on the reinvention of NNPDF, which included the [milestones](#) from the transition and the timeline for the reinvention. Below is the summary of comments from the audience.

TOPICS	SUMMARY OF COMMENTS
<b>General About Reinvention</b>	<ul style="list-style-type: none"> <li>• Reinvention looks well thought out</li> <li>• Support and advocacy plan is great</li> <li>• Host a call for families that did not attend</li> <li>• Circulate Mark Patterson video</li> <li>• Archive meeting for families to view</li> </ul>
<b>Donation/Fundraising</b>	<ul style="list-style-type: none"> <li>• Put a canister out in my place of business</li> <li>• Fundraise within my community</li> <li>• When people donate they like to get some item for the contribution</li> </ul>
<b>Resource &amp; Support Needs</b>	<ul style="list-style-type: none"> <li>• Advocate for core genetics</li> <li>• Respite care</li> <li>• End of life and legal issue support</li> <li>• Information on health care diagnosis and insurance</li> <li>• Support for newly diagnosed patients</li> <li>• Develop information and referral service</li> <li>• Provide basic Niemann-Pick Disease training</li> <li>• Help push FDA advocacy</li> <li>• Want more information on what the future services that are being planned</li> </ul>
<b>Executive Director</b>	<ul style="list-style-type: none"> <li>• Good idea to switch to professionally led organization</li> <li>• Need to know the responsibilities of the Executive Director and how time is spent</li> <li>• Executive Director's role is fundraising</li> </ul>

## NNPDF 2017 Family Conference Summary of Survey

At the end of the conference, participants filled out a survey. Below is the summary of comments.

TOPICS	SUMMARY OF COMMENTS
<b>Location and Timing</b>	<ul style="list-style-type: none"> <li>• Variable feedback; some liked because of location</li> <li>• Conference timing should be made well in advance by January so plans can be made for vacation</li> </ul>
<b>Schedule</b>	<ul style="list-style-type: none"> <li>• The overall comments were that the conference was very good and informative</li> <li>• Some suggestions were made that it was somewhat packed and need more time for discussion and questions</li> <li>• One comment noted that conference was too controlled, didn't have enough time for questions from the audience and wanted the members to be able to ask questions to primary investigators at the clinical trial presentation rather than the clinical trial break out rooms</li> </ul>
<b>Celebration of Hope</b>	<ul style="list-style-type: none"> <li>• Well done, consider a spiritual leader and a NPD tablecloth</li> </ul>
<b>Friday Morning</b>	<ul style="list-style-type: none"> <li>• Positive feedback, interesting, different but good, great speakers</li> </ul>
<b>Friday Afternoon</b>	<ul style="list-style-type: none"> <li>• Good sessions</li> </ul>
<b>Saturday Morning</b>	<ul style="list-style-type: none"> <li>• Appreciate joint discussions and being included in reinvention, need more time, very well thought out</li> </ul>
<b>Saturday Afternoon</b>	<ul style="list-style-type: none"> <li>• Not enough timing and ran too late, positive on support</li> <li>• More time for break-outs needed</li> </ul>
<b>Saturday Gala</b>	<ul style="list-style-type: none"> <li>• Good, positive, fun and well planned</li> </ul>
<b>Activity Zone</b>	<ul style="list-style-type: none"> <li>• Great</li> </ul>