



Vision of Hope  
Meeting the Needs of Today

## Transition Milestones and Reinvention Timeline

### NNPDF Milestones – What We Have Been Doing.

MONTH	NNPDF ACTIVITY
August 2016	<ul style="list-style-type: none"> <li>• Begin the Phase I Community Needs Assessment</li> </ul>
October 2016	<ul style="list-style-type: none"> <li>• Management Transition Team put in place</li> <li>• Complete Phase I Community Needs Assessment</li> <li>• Hire Transition Consultant</li> <li>• Review of grants management process started</li> </ul>
November 2016	<ul style="list-style-type: none"> <li>• Distribute Phase I Community Needs Assessment</li> <li>• Transition Consultant begins Phase II Feedback on Public Report to assess the will of the community to support a unified national patient group</li> </ul>
December 2016	<ul style="list-style-type: none"> <li>• Transition Consultant completes Internal Organization Assessment and presents it to the Board</li> <li>• Grants management review process completed</li> </ul>
January 2017	<ul style="list-style-type: none"> <li>• Ad Hoc Transition Team formed to support transition process</li> <li>• Transition Consultant and Board work to streamline office operations</li> <li>• Board engaged a new audit firm, as standard practice to periodically change firms</li> </ul>
March 2017	<ul style="list-style-type: none"> <li>• Phase II Community Needs Assessment Feedback complete</li> <li>• Ad Hoc Transition Team and Board decide to test community’s will to reinvent a national patient group</li> </ul>
April 2017	<ul style="list-style-type: none"> <li>• Ad Hoc Team oversees two community focus groups: one for NPC, one for ASMD to discuss the will to reinvent a national patient group</li> <li>• Ad Hoc Transition Team encourages Board to reinvent based on feedback from these two focus groups</li> <li>• Board continues to take on more day-to-day operations roles</li> </ul>
May 2017	<ul style="list-style-type: none"> <li>• Family Conference Committee formed</li> <li>• Conference planning begins</li> </ul>

## Reinvention Timeline – How we will get to the new NNPDF vision.

MONTH	NNPDF ACTIVITY
July 2017	<ul style="list-style-type: none"><li>• Started evaluating new family services intake process</li><li>• Started re-governance work</li><li>• Developed industry guidelines</li><li>• Board met with FDA</li></ul>
August 2017	<ul style="list-style-type: none"><li>• Created an initial Reinvention Plan</li><li>• Presented the plan to the community</li><li>• Establish <i>Reinvention Advisory Committee</i></li></ul>
September 2017	<ul style="list-style-type: none"><li>• Begin Corporate and Professional Partners reinvention campaign</li></ul>
October 2017	<ul style="list-style-type: none"><li>• Start NNPDF Reinvention Campaign with families and friends in Global Niemann-Pick Disease Awareness Month beginning in October</li></ul>
November - December 2017	<ul style="list-style-type: none"><li>• Begin recruitment for new <i>Executive Director</i> with <i>Reinvention Advisory Committee</i></li></ul>
February – November 2018	<ul style="list-style-type: none"><li>• New <i>Executive Director</i> reviews reinvention resource plan and develops strategic management plan</li></ul>