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Sanofi Genzyme hosted the first Rare Registry Futures Patient Advisory Council in Rotterdam on September 6 and 7th. At this meeting, representatives from several rare disease patient organizations from around the globe met to review the landscape of rare disease registries and discuss best practices for disease registry creation and management. The INPDR was recognized by patient leaders for its innovative design of being entirely patient-owned. Justin Hopkin of the NNPDF and Shaun Bolton, Data Manager for the INPDR, participated in the advisory council.

To mark Niemann-Pick Awareness month, Sanofi Genzyme will hold a Niemann-Pick Disease internal educational event at their Cambridge, MA (USA) headquarters on October 16th. The ASMD patient and family experience will be shared with company employees and leadership. Several ASMD individuals and families from throughout the US will attend the event.

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