Biographical Information for Jim Green  
President of the INPDA (International Niemann-Pick Disease Alliance)

Jim is the father of three children, Roy and Murray who were diagnosed with NPC and Ailsa who is not affected. Roy was diagnosed when he was 14 and is now 38; Murray was diagnosed when he was 11 and passed away, following a bout of uncontrollable seizures, when he was 18.

Jim is a retired school principal who, in 1991, founded the Niemann-Pick Disease Group (UK). He has been Chairman of that organisation until 2012. Jim was also an original member of the NNPDF Board when it was formed in the USA in 1992. He continued to serve on that board until 2004. In the twenty four years since 1991 Jim has witnessed many advances in research and understanding of NP issues. He has also met many researchers, clinicians and other people involved with these diseases. In 1991 there were no support Foundations and little or no information.

Jim has seen the growth of parent involvement, associations influence and has been witness to the huge difference people can make when they work together. In October 2009 this took another step forward with a collaborative venture between the NNPDF and the NPDG (UK) when they brought together NP Foundations from around the world to network and share information. This resulted in the formation of the “International Niemann-Pick Disease Alliance” the INPDA. Eleven countries are now full members and six more are starting in their own countries.