

Hello Everyone,

I want to begin by apologizing for not being with you at this year's conference. As some of you may have heard I will be attending my nephew's wedding in Bermuda this weekend, so although I will sincerely miss participating in the conference, at least it is for a good occasion!

Although I will be absent, I wanted to convey through this message my complete support for the re-invention plan that is being presented and discussed at this year's meeting, and my deepest commitment to continue to assist the NNPDP in any way possible. I have agreed to be part of the Reinvention Advisory Board, and will remain closely involved with the reinvention process and continue to offer my services as they are needed.

I have been involved with the NNPDP almost from its inception – over 20 years now - and I have seen it grow from a very small group of NPC parents who banded together to help one another cope with the serious challenges and difficulties of this disease, to a national organization that provides patient support and facilitates research for all of the NPD types. With this growth came challenges, which as you have heard is not uncommon for organizations such as this. But, through it all NNPDP has continued to play a vital role in helping families and patients cope with these diseases, and provided the most up-to-date and accurate information on research and new treatments.

I particularly want to emphasize in this message my personal view regarding the importance of maintaining NNPDP as an organization that serves all NPD families, regardless of whether they are affected with NPD A, B or C. The common challenges that all families affected by genetic disease face - fear, grief, thirst for information - do not distinguish between disease types, and we can all continue to learn and find strength by sharing these experiences among all individuals, regardless of the NPD type.

In addition, the FDA is actively seeking partnerships with national organizations such as this to better understand these diseases and to help guide them through new drug approvals. They require the input and advice of unbiased, national organizations that will provide the most accurate information, and NNPDP can serve a vital role in this regard. A national organization that represents all patients is also best positioned to foster the broadest and most productive industry relationships, rather than forming alliances with individual funding sources or companies.

I also continue to feel that there is much to learn on the scientific side as well – the individual disease types were not grouped under the same eponym by chance – they share many common features, and new research on one NPD type is undoubtedly going to benefit the other.

I wish you all a very productive and insightful conference, and I look forward to seeing you next year or perhaps even sooner.

Sincerely,

A handwritten signature in black ink, appearing to read 'Ed Schuchman', written in a cursive style.

Ed Schuchman