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## **NNPDF Pilot Program Community Industry Feedback (CIF) Pilot Program**

The NNPDF Board is committed to hearing your feedback, and bringing our larger, collective voice to our industry partners. As part of our process to understand what questions and thoughts you have regarding our pharmaceutical companies efforts, we are setting up a pilot program to get your feedback anonymously. We will be evaluating your feedback over the coming months and will then look at a way to make this pilot program part of a permanent function of our staffed Family Services Department. Below are questions you may have about the **Community Industry Feedback (CIF)** pilot program, and answers that we have provided.

### **Why is NNPDF piloting the CIF feedback program?**

- NNPDF is establishing the CIF program to help families and patients have an avenue to bring any questions or concerns about interactions with the pharmaceutical companies that we collaborate with to our attention.
- With the ability to gather valuable information from you, we will be able to understand the trends that are important to you as families and patients.

### **How will my feedback be used?**

- While you would raise any individual medical concerns to your clinical team, we see CIF feedback as an opportunity to better understand how we work and communicate general issues or concerns most effectively as a patient group with our pharmaceutical partners.
- Your anonymous feedback will also be valuable in helping us to better articulate the needs of our community as a whole in working with pharmaceutical companies.

### **Will we change the way pharmaceutical partners communicate with families?**

- The most important way a patient group can impact a company's communication is to begin with a policy statement like the one NNPDF Board of Directors established and has posted on our website.
- Each company has their own values and structure in the way they work. Public companies have obligations to report information to stakeholders in a timely fashion and operate in a highly regulated environment particularly around patient interactions. Setting guidance on how to interact appropriately and consistently with the Niemann-Pick Community serves the mutual interests of both the patient group and the company.

- When issues arise for a group of patients, these issues are best addressed by making them known to NNPDF. NNPDF can then work with the company to set a plan of action to mitigate future issues that could arise.

### **How do I participate?**

- To be involved in this **Community Industry Feedback** process, Missy Ward, NNPDF Board Secretary has volunteered to initially take your email feedback with the header “Community Industry Feedback”. Due to limited staffing capacity, Missy is serving this role for the evaluation period, and then we will consider ways to make this a permanent function within a staffed Family Services Department. You can reach Missy at [missy521@bellsouth.net](mailto:missy521@bellsouth.net). You may also send her your phone number if you are more comfortable providing feedback on the phone. Please allow 1-3 business days for response.

### **Where do I find information on current clinical trials?**

- For general information on a specific company and trial, please visit the links on the NNPDF website and [clinicaltrials.gov](http://clinicaltrials.gov) website.
- For specific patient/family questions, please use the company representative listed on the NNPDF website.