

Compounding Experiences with Parents: A Summary of the Introductory Meeting

Background:

The perspective of a parent with a chronically sick child is paramount in understanding not only the challenges of compounding but also the need, for commercial medications specifically formulated for children. This is particularly important in a context where parents are exhausted from caring for their child's, often, complex medical condition. Procuring the appropriate formulation for parents can be an additional task on already a large set of responsibilities that is unnecessary when medications are available in pediatric formulations in other jurisdictions.

On February 16, 2022, the Institute for Safe Medicine Practices Canada (ISMP Canada), Children's Healthcare Canada (CHC) and the Goodman Pediatric Formulations Centre (GPFC) brought together a small number of parents who had experience with the long-term compounding of medications for their child. The objective was to determine what is possible to advocate for this important cause.

Summary:

Prior to the meeting, the GPFC met with the parents to understand their story and to develop common themes from the parent's experiences. These can be found below:

- Compounding errors are made even if procedures and policies are in place to avoid compounding errors
- Medications not available at a local pharmacy sometimes could only be obtained at the pediatric hospital pharmacy
- Parents all lived in urban areas and finding a compounding pharmacy was easy –might not be the case for those living in rural areas
- Administration of compounded medicines difficult due to taste and texture
- Short shelf life of medication and issue requiring many trips to pharmacy
- Some parents have to go to great lengths to obtain the medication that they need
- Parents often are unaware that they are given a compounded medication
- Depending on the insurance plan – it can be costly for parents for their children's medications
- Compounding fees can vary from pharmacy to pharmacy
- Burden on parents to manage procurement of medication in an already complex situation of managing healthcare for a sick child-why is this acceptable?

Discussion During the Meeting:

- These children are so sick that parents do not need to add on more risk of using a compounded medication. These compounded medications lack consistency from pharmacy to pharmacy and although care is taken to ensure quality, human errors, can, and do occur.
- One parent shared their story that once they presented their prescription to their local pharmacy and that the pharmacist realized that the medication must be compounded, the pharmacist seemed not

confident to make the adapted medication. This, of course, adds a certain amount of stress to the parent and the confidence in the medication being prepared for their child.

- Another parent described using a compounded medication for their child and notice that a particular bottle had particles in the liquid. The parent returned the compounded medication to the pharmacist and the pharmacist indicated that the tablet had probably not been as crushed as it was normally. Although the pharmacist felt it was an acceptable preparation, the pharmacist did prepare another compounded formulation for this parent. Again, this situation imposes more unnecessary stress for the parents.
- There was some discussion regarding the groups ability to advocate and the parent's capabilities to find unique solutions to solve their compounding problems. However, there is a need to consider those who are not as aware, or capable, to find unique solutions and any advocacy efforts need to consider the large number of silent parents who are not able to navigate the complex Canadian healthcare system.

Possible Solutions:

- **Advocacy** at the political level is needed and champions need to be identified that can help bring these issues to light. A stakeholder mapping of political MPs or elected officials with an interest in pediatrics was discussed and some of them identified. In addition, identifying a group of parents who are willing to write to their local MPs and advocate for the cause is critical because it becomes personal and the MP becomes engaged. It was also mentioned that not all parents can, or know how to engage with their local MP. An alternate approach was suggested to send letters to all MPs, and the experience of those in this group is that this broad effort is generally not effective. It is much better to use personal storytelling with individual MPs (constituents).
- **Education** was also viewed as an important effort, and this from many view points. Parents, pharmacists, physicians all need to understand the impact on the patient and communications between all these parties should be improved with regards to compounding. For example, parents should be made aware when they are dispensed a compounded medication from their local pharmacy. Parents should be informed of the things to look out for when using a compounded medication.

Possible Next Steps:

- GPFC, CHC and ISMP Canada could develop a "**tool kit**" that could help parents advocate for this cause. CHC has experience with developing tool kits.
- Organising a "**Pediatric Medication Safety Day**" on the hill could be an important step to raising the issue with politicians in Ottawa.
- The development of an **infographic** on compounding to explain what it is and its advantages and disadvantages for parents.
- Using **vignettes** to tell the story of a Canadian child's experience compared with that of a US or European child where the commercial formulation is available.

What's Next:

Given the rich information exchanged during this meeting, the CHC, GPFC and ISMP Canada will convene and discuss what approaches would be best, building on the strengths and experiences of each organization.