

Innovative teaching tool for young children with severe hemophilia

Introduction:

In order for children to manage the psychological suffering at the time of diagnosis, defense mechanisms, especially denial, are necessary and adaptive. However, they can rigidify and become non-adaptive, hence impairing one's healthy adaptation (for example, through non-adherence to treatment). A teaching tool proves to be necessary in order to help parents and healthcare providers better approach the topic of hemophilia with young children.

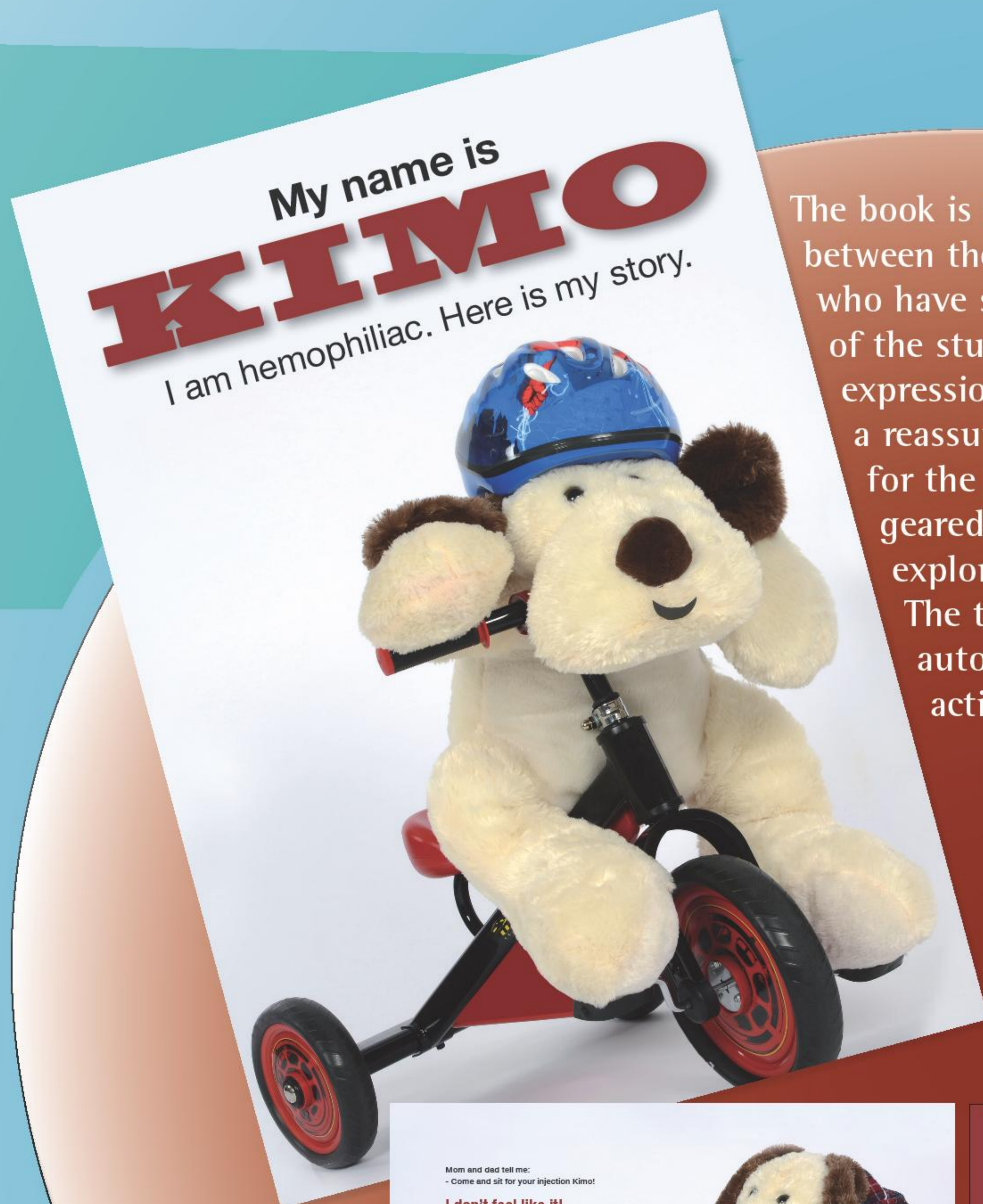
Objectives:

To provide a tool for healthcare providers and for parents of children with hemophilia that can promote adaptation to the illness and can support the child's mastery of hemophilia and its treatment.

Methodology:

The tool suggested consists of a life-size book with large illustrations and a simplified vocabulary adapted for young children. This tool will be used in the context of parent-child workshops led by the nurse navigator and the psychologist. This workshop consists of addressing children aged 0-5 by telling them about hemophilia via the stuffed animal represented in the book. The exchange will be done using real words, by acting out the treatment, by talking about emotions with the stuffed animal, by playing games with the group, and by allowing for a relaxing time with the parent.

The book is intended for children between the ages of 0 and 5 years who have severe hemophilia. The use of the stuffed animal facilitates the expression of the child's emotions in a reassuring context. The book also allows for the development of parental skills geared to promote safe discovery and exploration in the child with hemophilia. The tricycle symbolizes the child's increased autonomy by taking part in a pleasant and safe activity.



Explanation of the illness and of the treatment in order to maximize the child's understanding, participation, and adaptation.



I AM ANGRY!



Identification, expression, and normalization of feelings with regards to injections



The treatment, the routine, and suggested adaption strategies

The release of this book is scheduled for September 2014.

Published by Sainte-Justine Editions in Montreal, the book will be distributed by the Canadian Society of Hemophilia (www.hemophilia.ca)

Results:

The book will contribute to the child's acclimation to the treatment by naming the difficult emotions it can evoke and, in turn, help the child to better tolerate these emotions, leading to healthier adaptive mechanisms.

Conclusion:

This tool enables helping children to adapt to their treatment by offering them a simple and age-appropriate explanation. Furthermore, it allows for the elaboration of emotions brought on by the medical condition. As such, the long-term therapeutic goal of this approach is to lead the child towards a better control of the illness instead of denying its existence and its impacts

Contribution to the evidence/practice base in bleeding disorders:

This book has significant potential for healthcare providers in hemophilia treatment centers. It can serve as a teaching instrument for young children and can help them acclimate to painful medical procedures and better understand the limits imposed by their illness.

