

The FOXP1 Foundation plays an important role in encouraging the use of “Social Precision Medicine”.

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Introduction

As genome sequencing advances, so will the need for genetic Peer Support Groups such as the FOXP1 Foundation Support Group. These groups support members in unique ways that differ from the standard clinical care patients receive. In the FOXP1 community, parents/carers share information about their child's symptoms, treatment plans, personal experiences, emotions, coping strategies, medications and therapies.

As more people are identified with FOXP1 Syndrome and we learn more about the genetic condition, the power to influence the diagnostic and treatment management processes will grow through Social Precision Medicine.

Method

The Social Precision Medicine theory was explored in two types of case studies.

The first case was one of a number of closed Facebook posts in the Friends and Family of FOXP1 Facebook Group. It met the selection criterion of focusing on behavioural traits, which yielded a greater than 25 post-response rate within a 12-hour period. The post was monitored for three days for common affirmative behavioural comments. Comments within the high-frequency posts were reported (Figure 1).

The second case study was one of 12 different conversations within the FOXP1 Foundation Informal Peer Support Group on different medium platforms (Figure 2). It met the selection criterion, focusing on symptoms and demonstrating the transfer of new clinical knowledge among members within the group.

Findings

Case Study 1

Social Precision Medicine was highlighted by identifying 44 comments about the common behaviours and symptoms often unique to the members' diagnosis from their shared posts. (See Figure 1). 73% of members in this closed Facebook group at the time the photo was posted (July 2018) responded in agreement to a post about the annoying compulsion post, 63% of them within a 12-hour time frame.

Case Study 2

Social Precision Medicine was exemplified in a conversation about overactive bladders between two FOXP1 Foundation Informal Peer Support Group members. One of the members commented that their child used medication to assist with controlling an overactive bladder. This conversation empowered the other member to discuss using bladder control medication for their child as an effective treatment with their clinical team, who had not considered using it. The conversation allowed the member to influence their child's treatment and management outcomes. This was evident by the member stating that their child had great success using the medication to treat the symptoms of an overactive bladder. (See Figure 2). Furthermore, the member who had initially recommended the overactive bladder medication has since changed to using the same less expensive medication for their FOXP1 child as the person to whom they originally suggested it. An overactive bladder is not a well-documented symptom of FOXP1.

Figure 1. Examples of the high-frequency comments about the “annoying compulsion” Friends and Family of FOXP1 Facebook Group post.

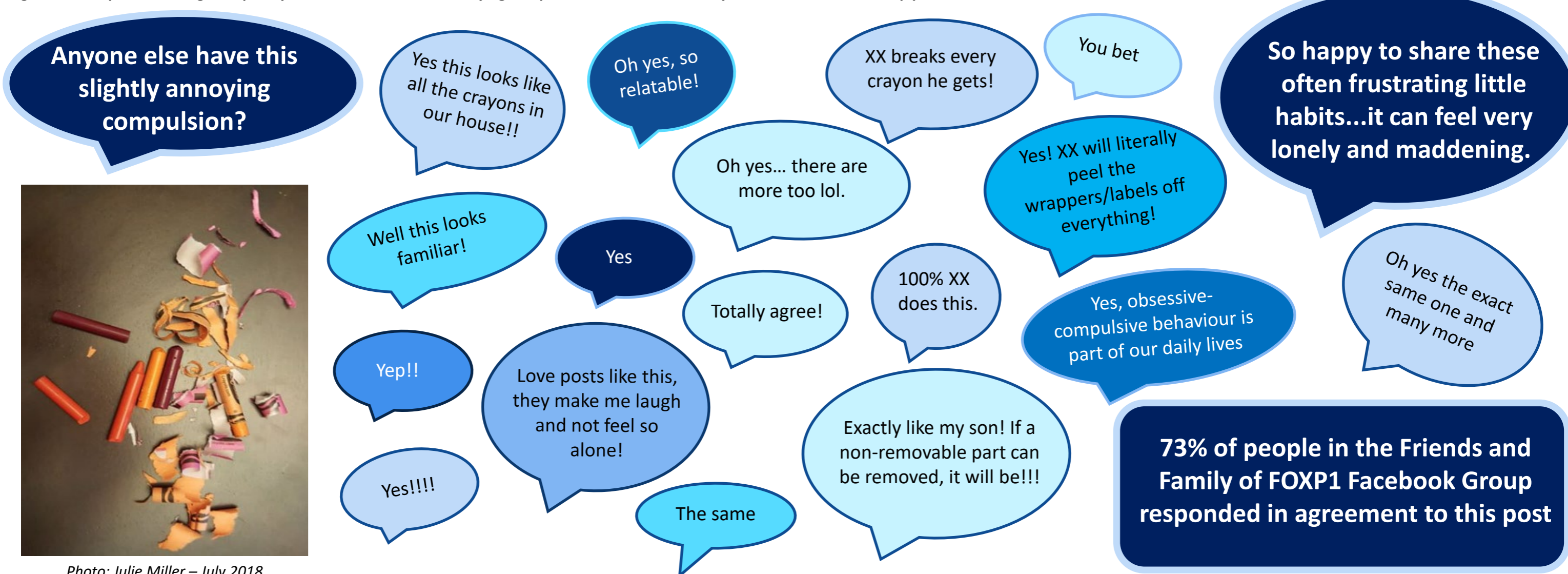
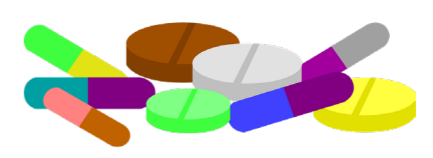
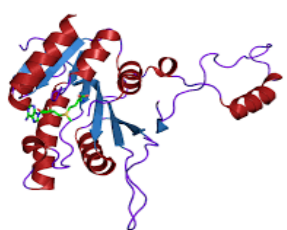


Figure 2: Timeline of the introduction of new medication into a person's clinical management plan based on knowledge gained from speaking with another FOXP1 parent



Discussion

Peer Support Groups collectively have the power to influence diagnosis and treatment management plans through a novel model called “Social Precision Medicine”.

Case Study 1 illustrates that nonphysical signs and symptoms found within Peer Support Group Members can still be of value and importance when making a diagnosis and considering different treatment and management plans. It demonstrates the importance of the Peer Support Group for this one compulsive behaviour trait despite it not being documented in the research papers associated with FOXP1.

Case Study 2 highlights that members can influence treatment and management plans with enhanced communication between Peer Support Group Members. This can have a flow-on effect with regard to members' well-being and mental health.

Both case studies demonstrate that members of the Peer Support Group unveiled novel and shared signs, symptoms and behaviour commonalities that were not previously considered during their clinical diagnostic process. The shared knowledge around diagnostic and treatment management information derived from Peer Support Groups can empower members to influence therapy, behavioural and coping strategies, and medication and treatment options clinicians did not consider.

Further investigations are required to analyse larger data sets to help determine the health and economic benefits of Peer Support Groups in influencing Social Precision Medicine.