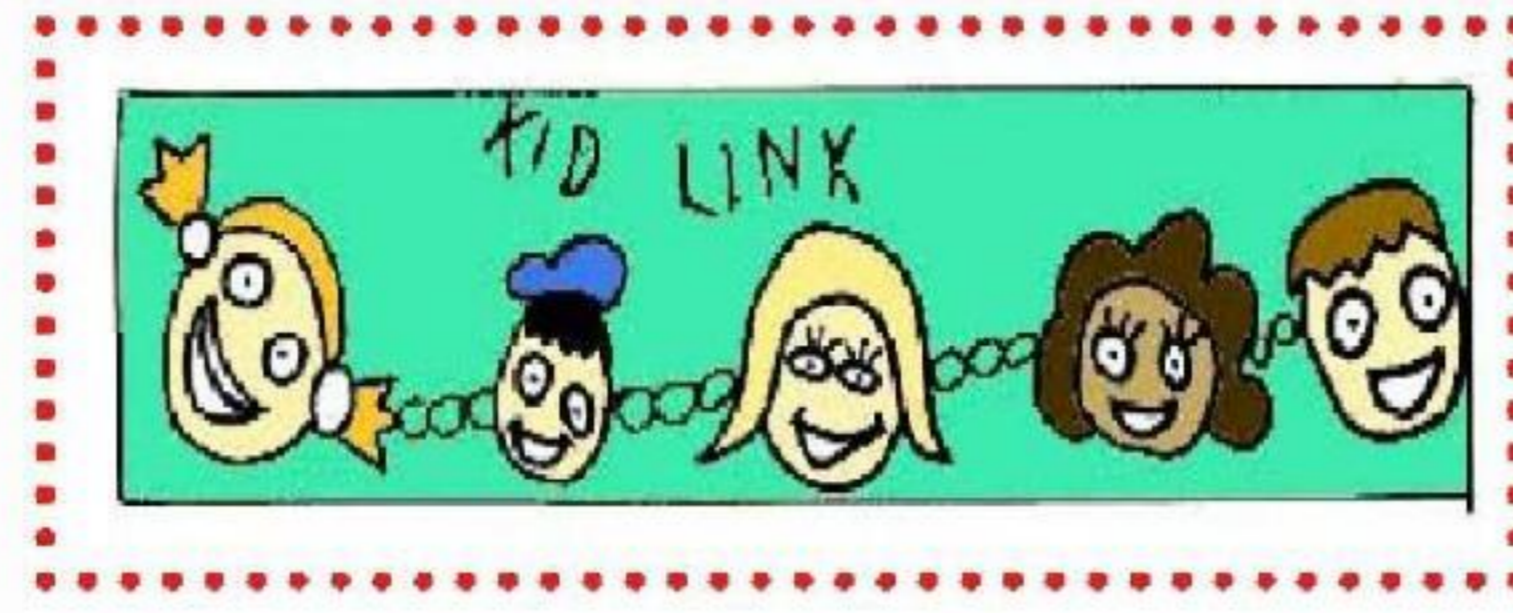


# Strategies to optimise inclusion and involvement of Young Men with Haemophilia

## Introduction and Objectives:

In 1998, the Irish Haemophilia Society (IHS) created a children's programme at events. Since then this has grown into four specific children and young adult programmes. These programmes help the children build strong relationships with each other and the Society, resulting in them remaining engaged with the IHS.

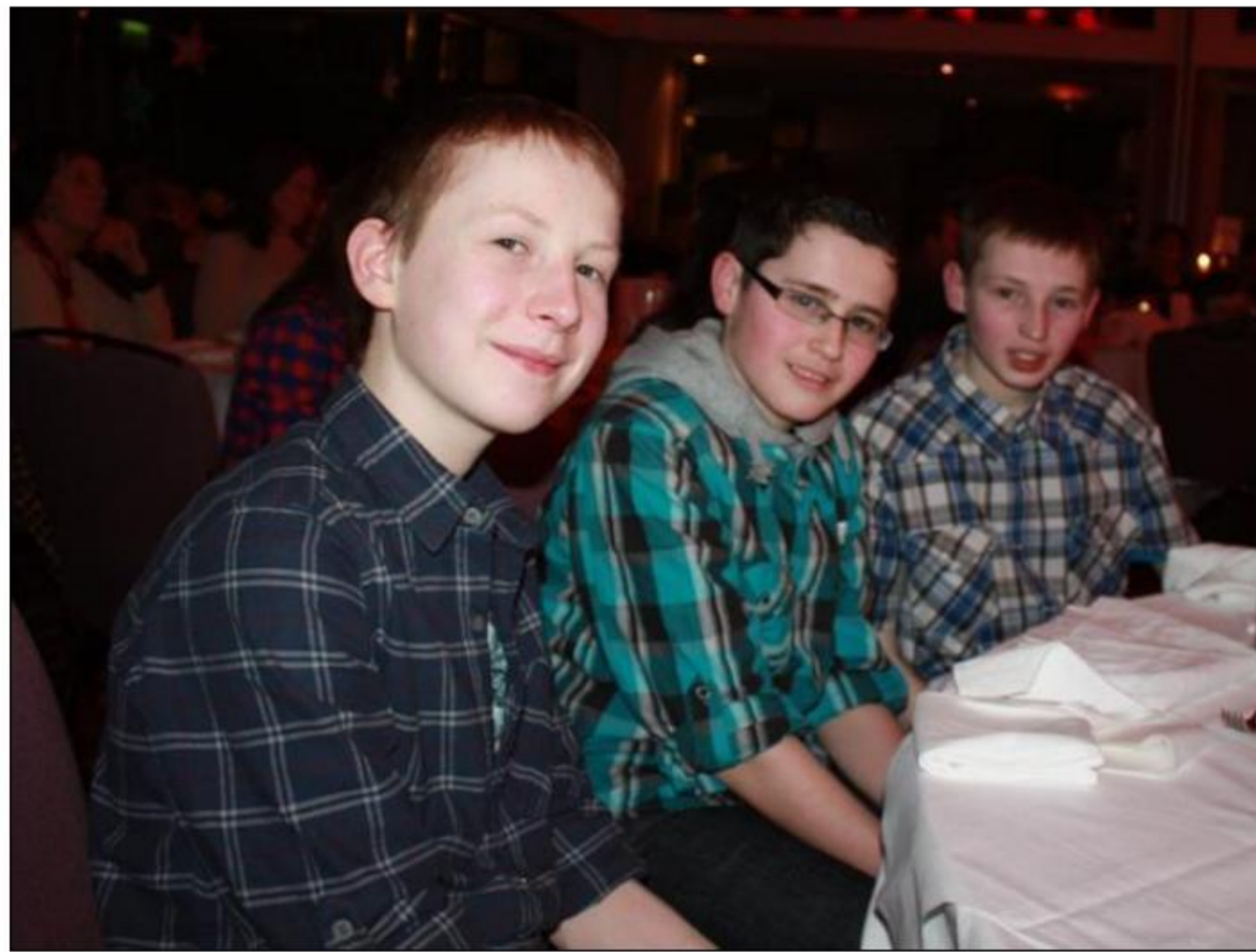
Authors: Brennan, F., Mc Auley, N., & Noone, D.  
Irish Haemophilia Society



## Materials and Methods:

In 2010, upon review of the Society's activities and support it became apparent that young men with bleeding disorders aged 18 to 35 were disengaged from the Society as they had never had any involvement personally. Historically, parents of PWH joined the IHS when their children were first diagnosed with a bleeding disorder, but as their children moved into adulthood, they began to lose contact with the IHS. The PWH would then re-establish contact later in life when haemophilia was important in relation to planning a family.

As part of the IHS strategic plan, a programme was set up to provide optimal support and services for young men with bleeding disorders. The aim was to re-establish contact with these young men using of phone calls and social media and organise a specific conference designed around the needs of these individuals for peer support and education.



## Results:

Once members fitting these criteria were identified through the IHS database, they were written to informing them of the conference and then contacted by phone from specific staff members. This was to initiate contact, increase the ease of registering and start to build relationships. As many of this age group work or attend college, it was discovered that the best option for contact was through texts, email or social media sites.



## Conclusion:

Initial interest was low when comparing potential group size to the actual attendance, especially from those with mild bleeding disorders with minimal symptoms. However, a sub group did attend and following the conference have remained in contact with the IHS and fellow delegates. The group are reluctant to join the main stream conferences as they feel more comfortable in a smaller group.. Future aims for this group are to maintain contact, develop relationships and improve involvement.

