

The development of a Youth Ambassador Programme

Author: Luke Pembroke, The Haemophilia Society UK
Co Authors: Laurence Woollard, Ria Peake, Rob Barnard, Hannah Yarnall

Introduction and objectives:

The UK Haemophilia Society identified the need for increased engagement of younger members and succession planning for future leadership. A recurring request of many members was to meet someone with a bleeding disorder who is living a positive and fulfilling life. The Society identified the need for five Youth Ambassadors; individuals comfortable and confident in sharing their experiences, to take a lead on projects and become organisation representatives.

Materials and Methods:

Adverts calling for expression of interest were placed in the membership magazine and on social media. Haemophilia Centre nurses were also asked to identify people aged 19-28 with a bleeding disorder to join the Youth Ambassador Programme.

Three young men with severe Haemophilia and two female ambassadors were recruited. These individuals have different life experiences, diagnoses and live in different parts of the UK. All are passionate about and dedicated to patient empowerment and advocacy. Following their recruitment, the Youth Ambassadors were introduced to the work of the charity and briefed on their expected roles. The Youth Ambassadors have been provided with ongoing training to help develop their public speaking, media activity and patient advocacy skills to enable them to fulfil their roles.



Youth Ambassadors help provide a variety of services. They:

- Co-ordinate and mentor at youth activity weekends
- Assist and contribute to Newly Diagnosed Family weekends
- Write articles for the Society's HQ members' magazine
- Participate in European training workshops and networking events
- Review a range of materials in order to provide a younger patient's perspective of living with a bleeding disorder / condition.

Results

The Youth Ambassadors support and empower younger members by listening to their concerns, encouraging them to be active and begin self-treatment.

During Newly Diagnosed weekends, Youth Ambassadors engage with and listen to new parents. The advice and reassurance offered by the Youth Ambassadors provides much relief for many parents who have just had their child diagnosed with a bleeding disorder.

Several Youth Ambassadors have joined staff and trustees at training provided by the European Haemophilia Consortium (EHC) on youth leadership (photo of people at EHC), organisational leadership as well as new technologies in Haemophilia. This has enabled the Youth Ambassadors to understand the range of work an NMO undertakes, the challenges it faces and the decisions that need to be taken.

Youth Ambassadors now actively contribute to the continued development of The UK Haemophilia Society and the services it delivers. Youth Ambassadors' experiences have equipped them with transferable skills and are now beginning to plan and implement new services the NMO can offer to the UK bleeding disorder/condition community.

Conclusions

The Youth Ambassador programme successfully engaged young people at a time when it is difficult to do so. The establishment of the Youth Ambassador programme develops and prepares future leaders for the UK Haemophilia Society, helps to ensure the NMO's longevity, enhances the quality of services and demonstrates the diversity of the bleeding disorder community in the UK. Youth programmes should be a priority for any NMO because of their positive impact on the future of the organisation.

"You're an inspiration and a breath of fresh air when it comes to something that can be so daunting. Thanks for all of your input and the support you've offered."

"Laurence is a fantastic advocate for Haemophilia. He was very matter of fact, sharing his experiences and consequences of not administering regularly. Again, meeting a young man who has very much lived his life to the full is so reassuring for my son's future."



THE
HAEMOPHILIA
SOCIETY

Poster number 40



Poster
Presented at:

DOI: 10.3232/jso.eu.WFH2016.2016

Capacity Building
Luke Pembroke

40--PP--W

910ZHHM