

FUTURE OF ADVOCACY: WHO ARE THE NEW LEADERS?

1 December HAAB Webinar: Discussion Report

On Tuesday 1 December, the Hemophilia Advocacy Advisors Board (HAAB) held a dedicated webinar to discuss the importance of succession planning when looking to the future of advocacy and advocacy organizations.

In addition to Dawn Rotellini's (COO, National Hemophilia Foundation, USA) presentation on what succession planning is, why it's important and what it takes to grow the next generation of leaders, graduates from Step Up Reach Out (SURO*) and International AFFIRM* Programs Steven Mah (Member of the Board of Directors for the Global Blood Disorder Foundation, USA) and Carlos Melgarejo (Fundacion Metamorfosis, Guatemala) discussed their experiences of becoming advocacy leaders. The webinar then concluded with an open discussion exploring the topics raised.

Below is a summary of the key points discussed:

The importance of leadership development

- Succession planning and leadership development are part of the same process, ensuring there are team members ready to resume management roles when current leaders must retire.
- It's important that succession planning is part of the leadership's culture, to ensure organizational continuity and that there are trained team members ready to fill positions as they become vacant.
- Training is vital to the success of these new leading individuals – it's important individuals are given the tools required to be successful in management positions.

5 competencies of a leader

- Communication, self-management, the ability to facilitate a group discussion / meeting, career skills and emotion intelligence were discussed as the top 5 skills required of a leader.
- When training a young leader to take up a management position, these skills should be developed and trained.
- Failure was discussed as not always being a negative, but as an opportunity to learn from mistakes when learning and training to become a leader.

Societal barriers

In some societies, it's unusual for younger members of the team to proactively seek out roles in leadership teams. We discussed how to encourage younger people to take up such roles:

- Foster talent from a young age, giving autonomy and responsibility to young leaders who help to manage Summer advocacy training camps for example.
- Create unity among these communities, to help people understand that succession planning is vital to organizational success.
- Identify what young leaders' strengths are and allow them to grow by delegating tasks that play to those strengths.

A male dominated environment

Women are often left feeling unempowered, given the hemophilia community's leadership male dominance. In addition to this, given the male dominance of the patient population genetically, women with hemophilia are often secondary, despite the complications they do experience. Possible solutions include:

- Creation of women committees as well as purposeful education for young women within the community are both important to empowering these individuals.
- India's woman's committee was discussed as an example of this; created only 8 years old, they now plan and implement an annual women's conference, with now over 100 attendees. Their NMO, HFI, is in full support of these activities.
- In addition to this, in Pakistan, a country which has traditionally been male dominated, each chapter of the Hemophilia Society now has an active women's committee and are developing strong potential leaders.
- The HemLEAD program has now been opened to women, also offering a new avenue for developing and empowering young women in the hemophilia community.

Young leaders' engagement

- Given that in most countries prophylaxis is available to all patients, the younger generation may have become less engaged with advocating for improvement to care.
- Considering this, engaging young advocates to continue advocating for care was discussed, given that maintenance of care is of course a priority for all markets, but a top priority for some less developed economies.
- For those economies where prophylaxis is widely available, advocating for innovative therapies such as gene therapy was discussed.

Understanding the local environment

- Simple and accessible online content is needed to help people understand the need for better treatment.
- Understanding how people interact with one another within the organization was discussed, as well as with stakeholders within the external environment. Recognizing this will allow young leaders to connect with and educate the community – a more connected and educated community is more powerful.
- In addition to this, local laws and patient rights must be understood to advocate effectively. In order to effectively advocate within the local community, understanding patient laws and rights is necessary.

Delegation

- The ability to delegate the right tasks to the right people, with the right skills and experience, is necessary in becoming an effective leader.
- In addition to this, ensuring that advocacy fits into your life and ensuring you have the capacity to effectively complete the tasks you've assigned to yourself is important.

Long-term planning

- Succession planning must be executed with a timeframe in mind. For example, leadership development and succession must be planned so that within the timeframe that the current leadership will be retired, new leaders will be trained to take their place.
- The future leaders must have their own vision for the future of the community and should be able to articulate this to current leaders. This new vision can then be built into the long-term plan of the organization, providing organizational continuity.

**Step up and Reach out (SURO) and AFFIRM programs are delivered by the Global Blood Disorder Foundation (GBDF) and sponsored by Bayer.*