SPEAKING AS ONE VOICE: UNITING AND EDUCATING ADVOCATES

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INTRODUCTION AND OBJECTIVES:

Patient advocates have unique and direct insight into the needs and challenges of the hemophilia community. They often serve as their voice on key issues, so it is critical for them to have the tools and experience to effectively advocate for their constituents. To help support the efforts of this important community, we created a platform for them to come together to discuss the issues they face and empower them to affect change in their local communities.

MATERIALS AND METHODS:

In 2011, an international advocacy board, Hemophilia Advocacy Advisors Board, was established to help identify unmet advocacy needs in the community and create programs that would galvanize advocates and help them drive impact in their communities. One of the immediate areas of need recognized by the Hemophilia Advocacy Advisors Board was the importance of educating and uniting the community.

To help address this need, the Hemophilia Advocacy Advisors Board – sponsored by Hemophilia Solutions by Bayer – created the Global Haemophilia Advocacy Leadership Summit, a gathering of top hemophilia advocates from across the globe, to discuss issues critical to the advocacy community.

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COUNTRIES THAT PARTICIPATED IN 2013:

ARGENTINA	CZECH REPUBLIC	SAUDI ARABIA
AUSTRALIA	IRELAND	SOUTH AFRICA
BELGIUM	JAPAN	TAIWAN
CANADA	KOREA	TURKEY
CHINA	MEXICO	USA
COLOMBIA	POLAND	VENEZUELA

RESULTS:

The inaugural event in 2012 attracted 23 advocates from 14 countries – including the UK, Brazil, South Africa, Italy, Canada, Mexico and the US and covered the topics of economics in advocacy, government relations and communications. The Summit offered participants an opportunity to learn from leading experts and from each other through presentations, case studies, discussions, workshops and networking opportunities.

Due to the success of the first event, the Hemophilia Advocacy Advisors Board hosted a second Summit in December 2013, which focused on the evolving communications landscape – from traditional to social media – and how it affects advocacy in the hemophilia community. Thirty-two participants representing 18 countries, including Australia, Taiwan, Saudi Arabia, Korea, Venezuela, Colombia, Ireland, attended.

CONCLUSION:

The Global Haemophilia Advocacy Leadership Summit – developed by the Hemophilia Advocacy Advisors Board and Hemophilia Solutions by Bayer – provides advocates with a platform to learn the tools and strategies they will need to create change in their own communities.

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