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### **Background/introduction**

**BE** is a *Canadian pilot program* that evolved out of the findings of HERO (Hemophilia Experiences, Results and Opportunities). HERO was a global QoL study that focused on psychosocial aspects of life for people with hemophilia. Three main themes arose, one of which was vocation, and from this the Canadian BE pilot project was born. Canadian results pointed to the fact that hemophilia has a **substantial impact** on the working life of people with hemophilia and parents of people with hemophilia. **53% of people with hemophilia** and **27% of parents of people with hemophilia** responded that hemophilia has had a very large or moderate impact on their working life. Novo Nordisk sought the advice and feedback of a group of healthcare professionals from various hemophilia treatment centres (HTCs) in Canada, and formed the Canadian HERO Advisory Board.

### Method

The age group chosen for participants was 16 to 18 years, because this is an important and highly impressionable time of life with respect to understanding and choosing future academic courses and suitable careers. The pilot took place with the support of two pediatric HTCs in Canada, representing both larger (urban) and smaller (rural) cities. The Hospital for Sick Children in Toronto and Alberta Children's Hospital in Calgary were chosen with a target of 10 boys between both centres. The experience would take the form of up to five job shadows per participant.

### What is a job shadow?

It refers to spending a defined period of time "shadowing" one individual at an organization through their daily tasks. Shadowing provides insight into a specific role/career to begin to understand the nature of the job.

Information packages were created for both participants and employers. The role of the HTC was only to identify possible participants and send the official information package to them outlining the program. It was determined that because the HTC teams were "hands-off," there was no need for ethics approvals.

# A youth employment pilot program:

### **Core objective**

To provide assistance in obtaining meaningful employment experience to selected, interested participants with hemophilia, aged 16 to 18 years.

MISSION TO ENABLE YOUTH WITH HEMOPHILIA TO REALIZE THEIR CAREER POTENTIAL.

VISION MEANINGFUL WORK EXPERIENCES AND CAREER COACHING FOR YOUTH WITH HEMOPHILIA.

### **Participating employers**



### Results

### **Total Participants** (8 Toronto, 2 Calgary)

Total job shadow requests at start

Unfulfilled requests\*

Total fillable requests

Job shadows completed

% Completion

Average job shadows per participant

Number of employers engaged

\* Unfulfilled due to difficulty in finding employers to participate, for example butcher, oncologist, neurologist, game developers (two requests), accountant, sports agent. This also accounts for one illness, two cancelled opportunities and change of heart since the original request. Of the total fillable requests, there were some challenges in scheduling employers' times with participants, and some employers became unavailable. Also, some participants' school schedules, as well as one personal issue, prevented further job shadowing opportunities from taking place.





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10
43
12
31
25
81
2.5
26

### **Participant evaluation**

Each participant was asked to complete an evaluation form for every job shadow they attended. Below is a compilation of the answers to one important question.

Before job shadow\* 73% After job shadow\* 86%

- 90% rated the advice as helpful\*
- 91% felt that this experience met their original goals\*
- 91% rated the experience enjoyable\*
- 100% of participants received career advice regarding education requirements
- 73% regarding typical career flow and 73% regarding career options stemming from specific education
- \* Responses reflect ratings greater than or equal to 5.

### Conclusions

employers.

**Participants** reported that they gained valuable insight/mentoring from their job shadows for future education requirements. The opportunities to view different types of work and engage with employers were helpful at a time when they are making decisions about their academic courses.

**Parents** expressed concern over the importance of career choice and appreciated the opportunity for their sons to experience different types of work. Career choice is a concern for boys with hemophilia and their parents.

**Employers** (a majority) reported that the experience was worthwhile and provided knowledge about hemophilia. They recognized the value of the job shadow experience to the participants and were supportive. An expanded program will be offered throughout Canada.

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### Highlights from participant evaluations: scale of 1-7 (low to high) "Describe your comfort level in pursuing this type of work."

### Our conclusions were derived from three stakeholders, the participants, the parents and the











