



Assisting, educating, and advocating for the bleeding disorders community.

## Summary Report from Blood Brotherhood and Families Survey

### Joint Health Data Analysis

11-22-2019

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## Introduction

As part of the collaborative relationship between Hemophilia Federation of America (HFA) and the Centers for Disease Control and Prevention (CDC), HFA developed several surveys and collected information in 2017 from participants in the Blood Brotherhood and Families programs. The purpose of these analyses from the survey data was to understand the gaps in knowledge and awareness regarding physical activity, joint health and inhibitor development, testing, and risk factors. The findings shared in this report summarize our findings and provide recommendations on the utilization of these results to improve health outcomes for Persons with Hemophilia (PwH). Results from surveys are being used to inform HFA efforts.

## Survey Results

The results from these data analyses have been used to inform the development of interventions to address the following:

- Increase knowledge and awareness about and participation in safe physical activities for people with hemophilia

## Blood Brotherhood Surveys

### Joint Health

These results were limited to men aged 18 and over who reported a primary diagnosis of Hemophilia A, Hemophilia B and/or vWD. This dataset had 120 respondents that met inclusion criteria.

### Overall Respondent Information

The largest age group of respondents were aged 50-59 (28%), closely followed by the 30-39 (26%) age group. Most respondents resided in the Midwest, labeled as Region 2 (38%). Most participants (78%) had a primary diagnosis of Hemophilia A and had a treatment plan that included prophylaxis (67%).

Age of Participants	Percentage of Participants
18-29 years	17%
30-39 years	26%
40-49 years	14%
50-59 years	28%
60+ years	15%

Region*	Percentage of Participants
Region 1 (Northeast: CT, ME, MA, NH, RI, VT, NJ, NY, PA, PR)	15%
Region 2 (Midwest: IL, IN, MI, OH, WI, IA, KS, MN, MO, NE, ND, SD)	38%

Region 3 (South: DE, FL, GA, MD, NC, SC, VA, DC, WV, AL, KY, MS, TN, AR, LA, OK, TX)	31%
Region 4 (West: AZ, CO, ID, MT, NV, NM, UT, WY, AK, CA, HI, OR, WA)	15%

Primary Diagnosis	Percentage of Participants
Hemophilia A	78%
Hemophilia B	16%
vWD	7%

Treatment Plan	Percentage of Participants
Prophylaxis	67%
On-Demand	27%
Do not know or No formal Plan	6%

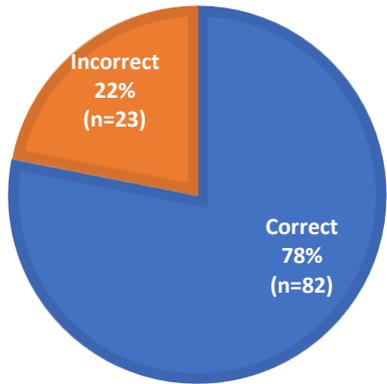
\*Region was determined using the Health Resource Service Administration (HRSA) definition of geographic region.

#### Safe Physical Activity Knowledge

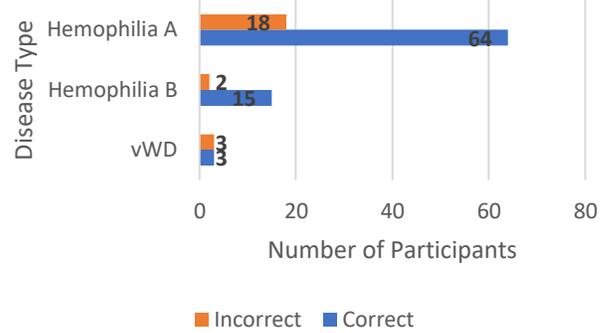
Among those with a primary diagnosis of Hemophilia A, 78% of participants correctly identified one or more safe physical activities for PwH. Safe physical activity was defined as respondents selecting swimming and did not select skiing, trampoline or wrestling. Men who lived in Region 2 (Midwest) and Region 3 (South) accounted for 70% of those who correctly identified safe physical activities. Also, 70% of participants who correctly identified safe physical activities had a treatment plan that included prophylaxis.

Meanwhile, 22% incorrectly identified: Wrestling or Football or BMX Racing or Skiing (downhill) or Snowboarding or Skateboarding or Trampoline as a safe physical activity. Among those who answered incorrectly, 30% were men 30-39 years old and 30% were 50-59 years old. A significant portion of men did not complete the questions related to joint problems and pain.

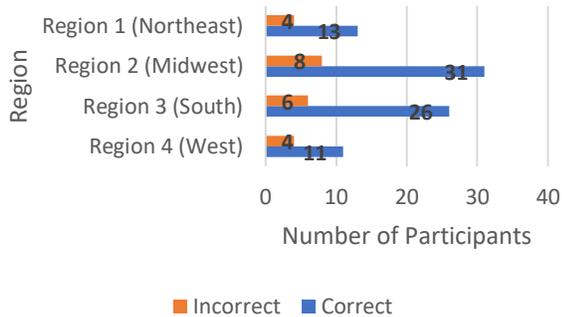
### SAFE PHYSICAL ACTIVITY



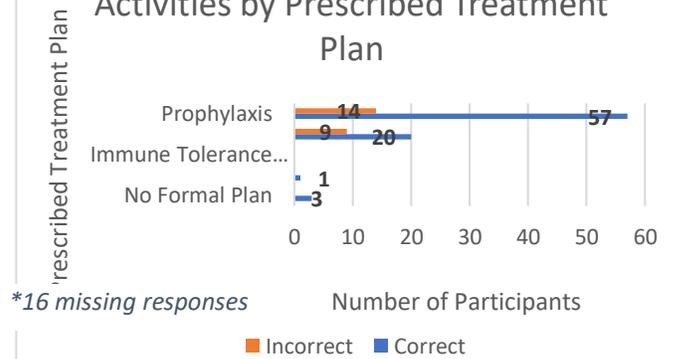
### Identification of Safe Physical Activities by Disease Type



### Identification of Safe Physical Activities by Region

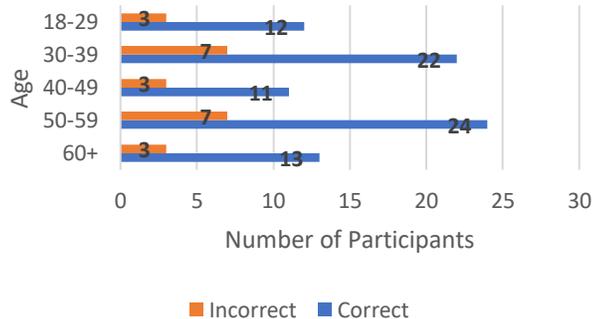


### Identification of Safe Physical Activities by Prescribed Treatment Plan



\*17 missing responses

### Identification of Safe Physical Activities by Age



\*15 missing responses

### Knowledge of Benefits of Regular Physical Activity

Correct benefits of regular physical activity were defined as the selection of either builds healthy joints, or positive impact on bones, muscles, and joints, or builds self-esteem and self-confidence. Benefits of regular physical activity was defined as incorrect if respondents selected decreases good cholesterol (HDL), increases weight, increases the risk of developing spontaneous joint bleeds. The majority of men, 78%, correctly identified one or more of these benefits and did not select an incorrect response.

Respondents aged 30-39 years old were the most likely to correctly identify one or more of the benefits of regular physical activity (30%) compared to other age groups. Men with Hemophilia A were more likely (84%) to correctly identify the benefits of physical activity compared to other disease types. Also, those who had a prescribed treatment plan of prophylaxis were more likely (65%) to correctly identify the benefits compared to other treatments.

Those aged 50-59 years old (39%), that lived in Region 2 (44%), and also reported always having joint problems (56%), were most likely to incorrectly identify the benefits compared to those in other age groups, regions, and lower joint problems frequency.

### Weight Intention

Over half (54%) of the men indicated they wanted to lose weight. Among those wanting to lose weight, the majority of them could identify safe physical activities and the benefits of engaging in physical activity. Approximately a quarter (23%) wanted to stay the same weight and 17% were not trying to do anything about their weight. Most men wanting to lose weight were between the ages of 30-39 (26%) and 50-59 (24%). Regarding disease type, most men with Hemophilia A (51%) and Hemophilia B (76%) responded that they were trying to lose weight. Approximately sixty percent of men who lived in Regions 1, 3, and 4 indicated they wanted to lose weight. More than half of those who were treated by prophylaxis (56%) or on-demand (52%) were more likely to respond that they were trying to lose weight compared to those on other treatment plans. Of the men who wanted to lose weight, 82% correctly identified one or more safe physical activities and 71% could correctly identify one or more benefits of engaging in regular physical activities.

### Current Physical Activity

The majority of men, 80%, reported being physically active at the time of the survey. There was a small percentage (29%) of those who were not active but also intended to lose weight. Even though these men were not active, all of them correctly identified the benefits to regular physical activity.

The most active men were between the ages of 30-39 years old and 50-59 years old. These two age groups were also most likely to report wanting to lose weight. The majority of men, 78%, who reported being currently active correctly identified one or more safe physical activities.

Among the men who were currently not active, 29% indicated that it was their intention to lose weight. Among the men who reported being currently active, 72% of men reported that they were not trying to do anything to lose weight. All the men who were not currently physically active correctly identified one or more of the benefits to regular physical activity.

### Intention for Physical Activity:

Most men (76%) reported a desire to become more physically active in the near future. More than half (59%) of the men who wanted to become physically active were also trying to lose weight. Also, most men (79%) who planned to be more active could also identify safe physical activities.

The majority, 76%, of men reported intention to become more physically active in the next 6 months, while 59% of the men who intended to become more active were also trying to lose weight. A larger percentage, 81%, of men who intended to become more active correctly identified one or more safe physical activities.

Over 50% of men who intended to become more physically active reported having joint problems that always or frequently limited their activities.

### Regular Physical Activity

About 70% of men were currently engaged in physical activity on a regular basis and 60% reported engaging in regular activity in the past six months. Most of these men were able to identify safe physical activities and benefits of regular physical activities.

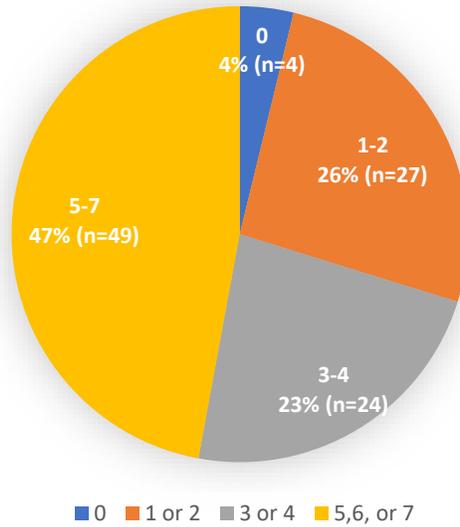
Of the 69% of men that were currently engaged in regular physical activity, over 50% of them were between the ages of 30-39 and 20-29. Also, in men that were currently engaged in regular physical activity, over 70% correctly identified one or more safe physical activities and benefits of regular physical activities. Of those who reported the intention to stay the same or not trying to do anything, many men still reported engaging in regular physical activity (56% and 67%, respectively).

Similar results were reported for regular physical activity in the last 6 months. Over half, 60%, of men reported having engaged in regular physical activities in the last 6 months. Of those men who reported being engaged in regular physical activity, 75% correctly identified safe physical activities and 81% correctly identified the benefits of physical activity. We also captured the number of days of current physical activity was reported by participants. Respondents reported an average of 4.17 days of current physical activity in a week with a median score of 4 days. Approximately half (47%) of men reported 5-7 days of physical activity in a week, of these, 29% were men who were 30-39 years old and 41% were from Region 2.

### Overall Days of Reported Current Physical Activity

Almost half (47%) of the respondents reported participating in physical activity for 5-7 days out of the week. Meanwhile, 23% of men reported 3 to 4 days of current physical activity in a week and 26% of men reported 1 to 2 days of physical activity in a week.

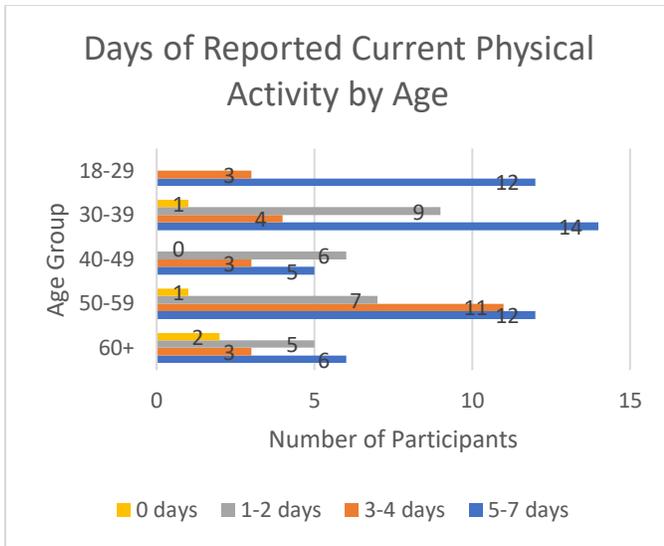
## Days of Reported Current Physical Activity<sup>1</sup>



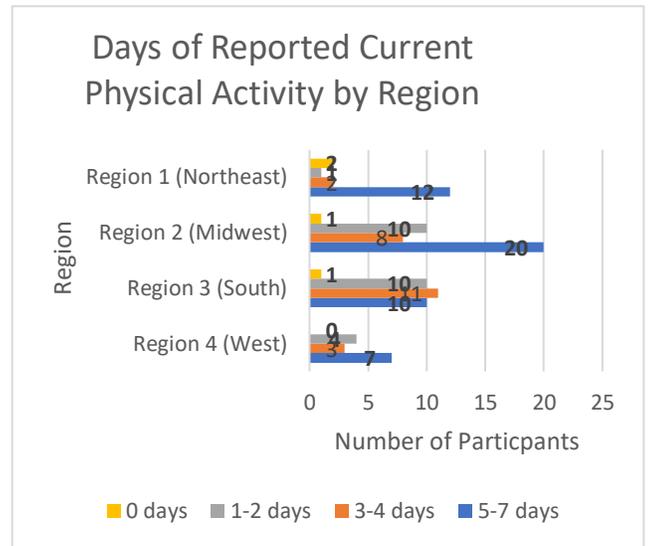
<sup>1</sup> 16 missing responses

### Overall Days of Reported Current Physical Activity by Age, Region and Disease Type

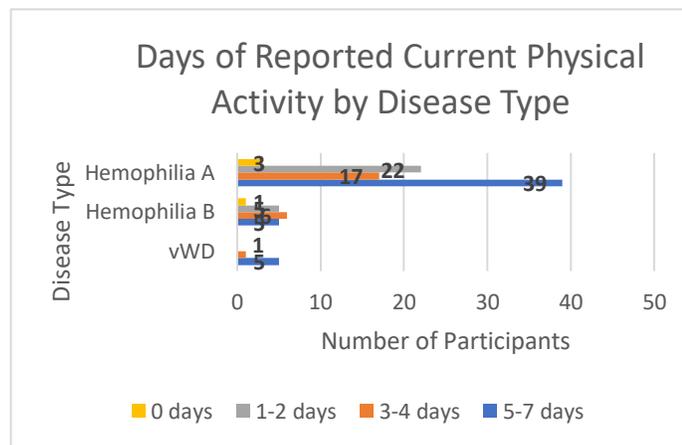
The majority of men (80%) who reported only 1 or 2 active days, 80%, lived in Regions 2 and 3. Men in age groups 40-49 and 60+ both had less than 15% of participants that were active 5 or more days. Approximately 46% of the men who were active 3 or 4 days were from Region 3 and 46% of these men were 50-59 years old. It is also worth noting that 48% of men with hemophilia A reported 5 to 7 days of current physical activities while 35% of men with hemophilia B reported 3 to 4 days of current physical activity.



\* 16 missing responses



\*18 missing responses



\*16 missing responses

#### Days of Physical Activity by Intensity (Moderate and Vigorous)

Respondents participated in moderate intensity physical activity for an average of four days a week and vigorous physical activity for 3 days a week. Those who were close to the average of 4 days (moderate intensity) were also the ones that most correctly identified safe physical activities and benefits of engaging in physical activity (42%).

Respondents reported an average of 4.17 days of engaging in moderate intensity physical activity with a median score of 4 days. Approximately 90% of men between the ages of 18-29 and 60 years and older both reported 3 to 4 and 5 to 7 days of moderate current physical activity. Also, the majority of men with Hemophilia A (85%) and Hemophilia B (78%) reported 3 to 7 days of moderate current physical activity. Men who engaged in 3 to 4 days of moderate intensity physical activity most correctly identified (48%) safe physical activities and benefits of engaging in regular physical activity compared

to those who engaged in physical activity at a higher or lower frequency. Men who engaged in 5, 6 or 7 days of moderate intensity physical activity had the most incorrect answers (46%) on safe physical activities and benefits of physical activities.

Men who reported engaging in vigorous physical activity completed an average of 2.93 days of physical activity a week with a median score of 3 days. The majority of men that reported vigorous physical activity were ages 50-59 (44%). Men who engaged in 1 to 2 days of vigorous intensity physical activity more correctly identified safe physical activity while those who most incorrectly answered which activities were unsafe reported 5-7 days of vigorous intensity physical activity. In terms of identifying benefits of regular physical activity, men who engaged in 3 to 4 days of vigorous intensity physical activity were most likely to answer correctly while those who reported 1 to 2 days of vigorous intensity physical activity were more likely to answer incorrectly.

### Joint Problems

Half of the men reported frequent joint pain while the other half reported never or rarely experiencing pain. Most of the men who had joint pain were 50-59 years old. Of the 41 men who responded to this question, 52% indicated they always or frequently had joint problems, while 51% indicated that joint problems rarely or never limited their daily activities. Additionally, men were asked about the number of days in the past month where pain affected their engagement in physical activity:

- 34% indicated 0 days of pain affected activity
- 44% indicated 1-15 days of pain affected activity
- 22% indicated 16-30 days of pain affected activity.

Exploring other factors, the majority of men who reported always having joint problems were ages 50 to 59 (56%). Also, approximately 55% of men with Hemophilia A and Hemophilia B both reported always or frequently having joint problems. Meanwhile, 81% of men reported that their joint problems did not limit their activities today, referring to the day in which they responded to the survey.

### Feeling Overwhelmed

The majority of men reported never or hardly ever being overwhelmed by their bleeding disorder. When respondents were asked about feelings of being overwhelmed by their bleeding disorders, 60% of men reported that they were never or hardly ever overwhelmed. Men who reported never feeling overwhelmed (31%) were ages 30-39 and 60 and older. Of those who correctly identified safe physical activities and benefits of physical activities, 33% and 36% of men reported hardly ever feeling overwhelmed, respectively.

### Physical Activity Information Source- HFA Activities

Patients reported receiving a moderate amount of physical activity information from HFA. There is a great amount of HFA Activities that participants were not aware of or had never participated in. When asked about their information sources on physical activity, patients reported that overall, they obtained a great deal (29%); a moderate amount/occasional (46%) and were never/rarely/ not aware (16%) of information on physical activity from HFA.

### Information Source

Physical activity information source	State/Local Chapter N (%)	HFA N (%)	CDC N (%)	NHF N (%)	Other BD org N (%)
Never	10 (24.4)	5 (12.2)	18 (43.9)	7 (17.1)	11 (27.5)
Rarely	9 (22.0)	1 (2.4)	6 (14.6)	4 (9.8)	9 (22.5)
Occasionally	7 (17.1)	13 (31.7)	5 (12.2)	13 (31.7)	8 (20.0)
Moderate	2 (4.9)	6 (14.6)	1 (2.4)	4 (9.8)	3 (7.5)
Great Deal	9 (22.0)	12 (29.3)	4 (9.8)	9 (22.0)	4 (10.0)
Not Aware	4 (9.8)	4 (9.8)	7 (17.1)	4 (9.8)	5 (12.5)
Total	41	41	41	41	40

When asked about which HFA activities they participated in to get information about health, wellness, and physical activity topics/education, participants expressed that they had never or rarely participated in or were not aware of HFA’s educational webinars.

	BB <sup>1</sup> Sessions at Local Member Organization	BB <sup>1</sup> Online Forum	Educational Symposium	Social Media Outlets (FB <sup>2</sup> , IG <sup>3</sup> , TW <sup>4</sup> )	Quarterly Newsletter, Dateline Federation	Website Resources (Educational Toolkits, web posts)	Educational Webinars
A great deal	7%	15%	24%	20%	22%	15%	10%
A moderate amount/ Occasionally	30%	25%	20%	31%	42%	24%	28%
Never, Rarely, Not Aware	43%	60%	56%	49%	36%	61%	62%

<sup>1</sup>Blood Brotherhood; <sup>2</sup>Facebook; <sup>3</sup>Instagram; <sup>4</sup>Twitter

## Families Survey

For the Families Survey, data analyses were limited to parent/caregivers with children up to the age of 25 years old with a primary diagnosis of hemophilia A, hemophilia B or vWD. Total respondents for analysis: 119 adults and 150 children of respondents. The majority of respondents were mothers or female caregivers (69%); lived in region 1 (27%), 2 (29%), or 3 (28%); and were between the ages of 40-49 (46%). Most caregivers (76%) only had one child and the majority of children were diagnosed with Hemophilia A (64%). Regarding treatment, 77% were treated with an infused factor and 59% were on prophylaxis.

### Overall Respondent Information

Caregiver Role	Number of Respondents (%)
A dad/male caregiver	33 (28%)
A mom/female caregiver	81 (69%)
A mom/female caregiver & A dad/male caregiver	4 (4%)
*1 missing	

Caregiver Region*	Number of Respondents (%)
Region 1 (Northeast: CT, ME, MA, NH, RI, VT, NJ, NY, PA, PR)	31 (27%)
Region 2 (Midwest: IL, IN, MI, OH, WI, IA, KS, MN, MO, NE, ND, SD)	34 (29%)
Region 3 (South: DE, FL, GA, MD, NC, SC, VA, DC, WV, AL, KY, MS, TN, AR, LA, OK, TX)	33 (28%)
Region 4 (West: AZ, CO, ID, MT, NV, NM, UT, WY, AK, CA, HI, OR, WA)	19 (16%)

Caregiver Age	Number of Respondents (%)
18-29 years	1 (1%)
30-39 years	33 (28%)
40-49 years	55 (46%)
50-59 years	26 (22%)
60+ years	4 (3%)

Number of Children	Number of Respondents (%)
1 child	90 (76%)
2 children	27 (23%)
3 children	2 (2%)

<b>Child Age</b>	<b>Child 1 [Number (%)]</b>	<b>Child 2 [Number (%)]</b>
6 months-2 years	4 (4%)	2 (7%)
3-4 years	5 (4%)	2 (7%)
5-8 years	29 (25%)	5 (17%)
9-12 years	22 (19%)	5 (17%)
13-17 years	33 (28%)	9 (31%)
18-25 years	25 (22%)	6 (21%)
<b>Total</b>	<b>118</b>	<b>29</b>

<b>Diagnosis</b>	<b>Child 1 [Number (%)]</b>	<b>Child 2 [Number (%)]</b>
Hemophilia A	77 (65%)	18 (62%)
Hemophilia B	23 (19%)	3 (10%)
VWD	19 (16%)	8 (28%)
<b>Total</b>	<b>119</b>	<b>29</b>

<b>Treatment Child</b>	<b>Child 1 [Number (%)]</b>	<b>Child 2 [Number (%)]</b>
Infused factor	94 (82%)	16 (57%)
Oral/nasal/topical products	16 (14%)	7 (25%)
Bypass/activated prothrombin complex	2 (2%)	2 (7%)
None	1 (1%)	1 (4%)
Other	2 (2%)	2 (7%)
<b>Total</b>	<b>115</b>	<b>28</b>

<b>Treatment Plan</b>	<b>Child 1 [Number (%)]</b>	<b>Child 2 [Number (%)]</b>
Prophylaxis	74 (64%)	9 (33%)
On-Demand	33 (29%)	14 (52%)
Immune Tolerance	1 (1%)	2 (7%)
No formal Plan	5 (4%)	1 (4%)
Do not Know	2 (2%)	1 (4%)
<b>Total</b>	<b>115</b>	<b>27</b>

\*Region was determined using the Health Resource Service Administration (HRSA) definition of geographic region

### Safe Physical Activity Knowledge

The majority of parent/caregivers could correctly identify safe physical activities. Among those who answered incorrectly, 74% had one child with bleeding disorders. Most parent/caregivers (74%) correctly identified one or more activities defined as safe physical activities. Region 2 had the highest percentage of incorrect responses (40.7%) and caregivers. Among parent/caregivers who correctly identified one or more activities defined as safe physical activities, 86% reported that their children

were currently active, and 72% indicated that their children intended to be more active within the next 6 months. Most parents/caregivers indicated that they had no weight concerns for their children, but 18 to 33 percent reported overweight concerns for their children (child 1 and child 2 respectively). A range of 40 to 62 percent of their children reported they never or rarely had joint problems.

When questioned about unsafe physical activity, 26% of parent/caregivers selected at least one or more unsafe physical activity which included wrestling, football, BMX Racing, skiing (downhill) or snowboarding, skateboarding, or trampoline. Among those who answered this incorrectly, parents/caregivers who reported having 1 child with bleeding disorders accounted for 74%. The majority, 92%, of these parents indicated that their children were currently active and 85% engaged in regular physical activity. Approximately 20% indicated that their children had joint problems. Parents/caregivers indicated that joint problems did not limit daily activities for their child whether they correctly (89%) or incorrectly (73%) identified one or more safe physical activities, respectively.

#### Benefits of Regular Physical Activity Knowledge

More than 70% of parents/caregivers identified one or more benefits of engaging in regular physical activity. The majority, 75%, of parents/caregivers correctly identified one or more benefits in engaging in regular physical activity. Most of these parents/caregivers (73%) were between the ages of 30-39 and 40-49 and lived in Regions 2 and 3 (59%). Parents that had at least one child between the ages of 5 to 17 (74%) were most likely to correctly identify the benefits compared to those with kids in other age groups. A large percentage, 87%, reported their children as currently active at the time of the survey, 72% intended to be active, and 81% engaged in regular physical activities. A small number, 25%, of parents/caregivers incorrectly responded that regular physical activity decreased good cholesterol (HDL), increased weight, or increased the risk of developing spontaneous joint bleeds. Over half, 54%, of these parents/caregivers had at least 1 child between 5 to 17 years old with a bleeding disorder.

#### Current Physical Activity

The majority of parents/caregivers (87%) reported that their children were physically active. Most of these children participated in moderate or intense activities and rarely had joint problems or pain that limited daily activities.

- 87% of children were reported to be currently physically active
  - Majority of these children's parents were 40 years and above (65%)
  - Children living in Region 2 and 3 accounted for 42% and 30% respectively
  - 63% were on prophylaxis treatment regiment
  - 87% of these children engaged in moderate intensity activities while 59% also reported engagement in vigorous intensity activities
  - Over 60% indicated rarely or never experiencing joint problems nor joint problems that limit daily activities\*
  - Over half of parents/caregivers reported 0 days of pain that would affect their children's activities

\*Significant number of missing responses

### Intention for Physical Activity

A little over 70% of parents/caregivers intended for their children to become physically active in the next 6 months. This intention was high in those with children who were overweight. A great percentage, 73%, of parents/caregivers indicated that their children intended to become more physically active in the next 6 months. The majority of these children lived in Regions 2 and 3 (both 30%) and their parents/caregivers were between the ages of 40-49 (41%). Most of the caregivers/parents who had concerns about their children being overweight indicated that they intended for their child to become physically active in the near future (86%).

### Days of Reported Current and Past Physical Activity

Approximately 85% of parents/caregivers reported that their children were physically active at least 5 days out of the week and had also been physically active in the past 6 months. Over 84% of parents/caregivers reported that their children were currently engaged in 5-7 days of physical activity in a week. Of those engaged in 5-7 days of physical activities, 38% were 5-8 years old while 20% were 9-12 years old, and 26% were 13-17 years old. Most, 63%, of these children were on a prophylaxis regimen. Among the 23% of those who engaged in 3-4 days of physical activities in a week, 45% were children between 18-25 years old. Approximately 84% of parents/caregivers reported that their children regularly engaged in physical activity in the past 6 months. A small number, 27%, of those engaged in the past 6 months were 13-17 years old while 24% were 5-8 and 13-17 years old.

### Days of Current Moderate Physical Activity

About half of children were reportedly engaged in moderate physical activities. Close to 40% were children aged 13-17 years old. The majority (60% and above) of parents/caregivers of children who engaged in moderate intensity physical activities could correctly identify one or more safe physical activities and one or more benefits in engaging in regular physical activities.

### Physical Activity Information Source- HFA Activities

When asked about their information sources on safe physical activity, parent/caregivers reported that overall, they obtained a great deal (19%); a moderate amount/occasionally (47%) and were never/rarely/not aware (34%) of information on safe physical activity from HFA.

### **Specific HFA Activities**

	<b>MO Sessions</b>	<b>Symposium</b>	<b>Social Media</b>	<b>Quarterly Newsletter</b>	<b>Website</b>	<b>Educational Webinars</b>
<b>A great deal</b>	16% (8)	24% (12)	20% (10)	27% (14)	14% (7)	10% (5)
<b>A moderate amount/occasionally</b>	49% (25)	43% (22)	59% (30)	51% (26)	53% (26)	31% (15)
<b>Never/Rarely/Not aware of</b>	35% (18)	33% (17)	22% (11)	22% (11)	33% (16)	59% (29)
<b>Total</b>	51	51	51	51	49	49

\* 68 missing responses for MO, Newsletter; 69 missing response for symposium, social media; 70 missing for website and webinar

## Conclusions from Blood Brotherhood and Families Survey Data Analyses

### Blood Brotherhood

Men appeared to be fairly educated on what were considered safe physical activities and the benefits of engaging in regular physical activities. However, 1 in 5 men still could not accurately identify safe physical activity and the benefits of physical activity. Education on different types and levels of safe physical activity and the benefits of said physical activity would be beneficial as the definition of what was considered as safe physical activity was broad.

It is worth noting that, the intention to engage in physical activity was higher than actual engagement in regular physical activity. Approximately 1 in 4 men were not engaging in the number of recommended days of physical activity. Furthermore, men were engaging in less vigorous activities during the week than recommended. Overall, knowledge and awareness about the benefits of physical activity and safe physical activities is needed along with an emphasis to move from intending to engage to engaging in moderate and vigorous safe physical activity. Among all of HFA activities, Symposium and the quarterly newsletter appear to be most effective.

### Families

#### Joint Health

With regards to identifying safe physical activities and benefits to engaging in regular physical activities, parents/caregivers appeared to be knowledgeable, but how safe physical activities were defined could be further explored. However, 1 in 4 caregivers still could not accurately identify safe physical activity and the benefits of physical activity. Levels of engagement in moderate physical activities were low (only half of parents/caregivers reported for their children). Quarterly newsletter, social media, and Symposium are HFA resources that parents and caregivers ranked the highest for physical activities education sources, while webinars did not appear to resonate.

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