

# Defining the Impact of Hemophilia: The Academic Achievement in Children With Hemophilia Study

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**ABSTRACT.** *Objectives.* We characterized a population-based cohort of school-aged children with severe hemophilia with respect to type of treatment, on-demand versus prophylaxis, and frequency of bleeding episodes in the year before enrollment. We also investigated the association between hemophilia-related morbidity, measured by number of bleeding episodes in the year before enrollment, and academic performance after adjustment for other factors known to have an effect on achievement. Finally, we explored the mechanisms for the association between bleeding episodes and academic achievement.

*Study Design.* This study was a multicenter investigation of boys 6 to 12 years old with severe factor VIII deficiency (clotting factor level <2%) receiving care in US hemophilia treatment centers. Children with a history of inhibitor, severe developmental disorder, significant psychiatric disorder, or insufficient fluency in English were excluded from the study. On-demand treatment was defined as administration of clotting factor on the occurrence of a bleeding episode. Prophylactic therapy was defined as a course of regular infusions for >2 months with a goal of preventing bleeding episodes. Academic achievement was measured by the Wechsler Individual Achievement Test. Quality of life was measured by the Child Health Questionnaire. Of particular interest was the Physical Summary (PhS) measure of the Child Health Questionnaire. The type of information captured by the PhS includes limitations in physical activity, limitations in the kind or amount of schoolwork or social activities the child engaged in, and presence of pain or discomfort.

*Results.* One hundred thirty-one children were enrolled, a median center recruitment rate of 77%. The mean age of the participants was 9.6 years, and approximately half of the participants had completed less than the fourth grade at the time of enrollment. Sixty-two percent of the children were on prophylaxis at enrollment, and 9% had previously been on prophylaxis but were currently on on-demand therapy. Two groups were defined: ever treated with prophylaxis and never treated with prophylaxis. For those ever treated, treatment duration ranged from 2.7 months to 7.7 years, with one half of the children treated with prophylaxis for >40% of their lifetimes; 29% had always been on on-demand therapy. Children in both treatment groups were similar with

respect to age, clotting factor level, parents' education, and IQ. The median number of bleeding episodes experienced in the year before enrollment for the cohort as a whole was 12. The median number of bleeding episodes in children on prophylaxis at enrollment was significantly lower than in children on on-demand therapy (6 vs 25.5).

The mean achievement scores were within the average range of academic performance: reading, 100.4; mathematics, 101.6; language, 108.1; writing, 95.4; and total achievement, 102.5. When children were categorized as above or below the study group median by number of bleeding episodes, those who had a low number of bleeding episodes ( $\leq 11$ ) had better total achievement (104.4 vs 100.6) and mathematics (103.6 vs 99.6) than children in the higher bleeding episode category ( $\geq 12$ ) after adjusting for child's IQ and parents' education. Treatment with prophylaxis per se was not associated with better test scores, but children who had been treated on a regimen of long-term prophylaxis (>40% of lifetime) and reported  $\leq 11$  bleeding episodes in the year before enrollment had significantly higher scores in total achievement (104.9 vs 100.6), mathematics (105.2 vs 99.6), and reading (104.0 vs 98.6) than all other children reporting  $\geq 12$  bleeding episodes in the same time period. Increased school absenteeism and hemophilia-related limitations in physical functioning among children with greater frequency of bleeding episodes were proposed as the mechanisms for lower scores. The number of bleeding episodes was positively correlated with school absenteeism (Spearman correlation = 0.23), and children with more school absences had lower scores in mathematics, reading, and total achievement, even after adjusting for the child's IQ and parents' education. Children with fewer bleeding episodes also had better PhS scores than children in the high bleeding episode category (48.4 vs 41.3). The mean PhS for children in the low bleeding episode group (48.4) was similar to that of the general US population (50), but the mean PhS for children in the higher bleeding episode group was almost a full standard deviation lower than the mean for the general US population. PhS scores were positively related to reading and total achievement scores after adjusting for IQ and parents' education.

Of interest and concern was a group of children who were reportedly being treated with prophylaxis during the year before enrollment ( $N = 18$ ) but whose bleeding events were not optimally suppressed. These children were 3 times as likely (33.3% vs 11.1%) to be receiving  $\leq 2$  infusions per week as children on prophylaxis who reported  $\leq 11$  bleeding episodes during the same period. A review of the sites of bleeding reported for the 18 children revealed that 12 (66.6%) experienced  $\geq 25\%$  of their bleeding episodes in the same joint.

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**Conclusions.** Each child should have the opportunity to achieve his or her potential. Control of a chronic disorder must include this important goal as well as the more commonly identified medical outcomes. This study has identified an important association between the number of bleeding episodes experienced and academic achievement in a cohort of school-aged children with severe hemophilia. The data support the assertion that therapeutic care programs in this population must not be evaluated only in terms of financial cost to achieve adequate musculoskeletal outcomes. Also significant are the individual and societal benefits of increased academic accomplishments if adequate suppression of hemorrhagic events can be attained. The number of bleeding episodes experienced, regardless of treatment regimen, should be followed to optimize the child's academic outcome. *Pediatrics* 2001;108(6). URL: <http://www.pediatrics.org/cgi/content/full/108/6/e105>; *hemophilia, academic achievement, quality of life, school absenteeism*.

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ABBREVIATIONS. HGDS, Hemophilia Growth and Development Study; WIAT, Wechsler Individual Achievement Test; WISC-III, Wechsler Intelligence Scale for Children—Third Edition; PhS, Physical Summary.

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The consequences of hemophilia can affect a broad range of physical, social, and academic activities among school-aged children. Identifying treatment modalities that can reduce musculoskeletal complications has been an important target of research. Treatment modalities that reduce musculoskeletal complications and limit cost are under study.<sup>1-4</sup> The effect of hemophilia on academic achievement also has been of interest to a number of investigators. Frequent absences from school, such as those experienced by children with chronic diseases, can interfere with the academic and social development of children.<sup>5</sup> Several reports in the literature document higher rates of school absenteeism in children with hemophilia than in others<sup>6-9</sup> and discrepancies between children's potential and achievement as they progress through the upper grades.<sup>8</sup>

Studying children enrolled in the multicenter Hemophilia Growth and Development Study (HGDS), Loveland et al<sup>10</sup> reported lower achievement than expected based on IQ at the baseline examination. Analyses of baseline and longitudinally collected HGDS data demonstrated associations between the functional severity of hemophilia, measured by abnormalities in coordination and gait, and academic performance.<sup>11,12</sup> Another HGDS report showed associations between prolonged hospitalization and lower achievement test scores in reading and spelling (Wong WY et al, unpublished data).

To extend observations made in the HGDS, the Academic Achievement in Children with Hemophilia study group was formed. Investigators from 18 comprehensive US hemophilia treatment centers collaborated in the collection of social, demographic, hemophilia-related, and psychological data from a population-based cohort of young school-aged children with severe hemophilia in an effort to further define relationships between hemophilia and academic performance. The study had 3 objectives:

1. Characterize the cohort with respect to type of treatment (on-demand vs prophylaxis) and frequency of bleeding episodes in the year before enrollment;
2. Determine the association between hemophilia-related morbidity, measured by number of bleeding episodes, and academic performance after adjustment for other factors known to have an effect on achievement<sup>13,14</sup>;
3. Explore the mechanisms of the association between frequency of bleeding episodes and academic achievement levels.

On-demand treatment was defined as administration of clotting factor on the occurrence of a bleeding episode. Prophylactic therapy was defined as a course of regular infusions for >2 months with a goal of preventing bleeding episodes. Investigators proposed 2 mechanisms for the association between bleeding episodes and academic achievement levels. First, frequent bleeding episodes could lead to diminished ability to take advantage of academic opportunities, in part because of school absenteeism. Second, factors that limit or interfere with physical functioning could have an effect by reducing the ability to complete schoolwork and participate in school-related activities. Examples of these factors include pain or discomfort such as that which accompanies a bleeding episode or is associated with chronic arthropathy.

## METHODS

### Design and Population

The Academic Achievement in Children with Hemophilia study is a cross-sectional, multicenter investigation of boys with severe factor VIII deficiency receiving comprehensive care in US hemophilia treatment centers. Potentially eligible children were identified through a census of the population of elementary school-aged children currently under care in the participating centers. Children 6 to 12 years old (dates of birth between January 1, 1987, and December 31, 1993) with severe factor VIII deficiency (<2%) were eligible to participate. Children with a history of inhibitor, severe developmental disorder, significant psychiatric disorder, or insufficient fluency in English were excluded from the study.

### Study Procedures

For purposes of standardization of data collection and study operations, a 2-day centralized training course for study staff was held. Psychological and parental report measures were administered by center psychologists masked to the type of treatment the child was receiving. All psychological data were reviewed centrally for validity and reliability by a psychologist skilled in their administration and masked to child's type of treatment. Project coordination, data management, and statistical analysis were completed centrally. The study was approved by human subject committees of collaborating institutions. Informed consent was obtained from parents or legal guardians; consent or assent was obtained from participants based on local institutional review board requirements.

### Data Collection

A medical record review and interview, including an extensive history of hemophilia-related events, demographics, and social, psychological, and academic history were conducted. Descriptions of bleeding episodes that occurred in the year before enrollment, including date, site, and cause, were recorded from logs kept by the parent or participant, and a detailed treatment history was obtained. It was recorded whether, since birth, the child had been treated with prophylaxis, defined as a course of regular

infusions for >2 months with a goal of preventing bleeding episodes and, if so, whether he was still on prophylaxis. Beginning with the most recent, the start and stop dates for all courses of prophylaxis were recorded. Children who had never been treated with prophylaxis were classified as receiving on-demand therapy. The percentage of lifetime on prophylaxis and the number of bleeding episodes reported in the year before enrollment were calculated for each participant. A physical examination and physical therapy assessment were completed. The primary outcome measure of the study, academic achievement, was measured by the Wechsler Individual Achievement Test (WIAT),<sup>15</sup> covering the areas of reading, mathematics, language, writing (third grade and older), and total achievement. The WIAT was selected because of its strong psychometric properties (eg, reliability, validity) and because it is the only achievement battery standardized with the Wechsler Intelligence Scale for Children-Third Edition (WISC-III),<sup>16</sup> the most commonly used individual intellectual ability measure for children in this age group. The Full Scale IQ from the WISC-III was used to account for its influence on WIAT scores. The Guide to the Assessment of Test Session Behavior,<sup>17</sup> a behavior rating instrument, was completed by examiners after each test session for both the WISC-III and the WIAT to determine validity of scores. The Child Health Questionnaire (PF50), a parent-reported measure of the child's quality of life, was administered. Of particular interest was the Physical Summary (PhS) measure of the Child Health Questionnaire (Appendix). The PhS has a mean of 50 and a standard deviation of 10 in the general US population.<sup>18</sup>

### Statistical Methods

Linear regression was used to assess the relationships between achievement scores and number of bleeding episodes, type of treatment (prophylaxis versus on-demand), school absenteeism, and PhS score after adjusting for the child's IQ and the parents' education. Student *t* tests or Wilcoxon rank-sum tests were used to compare continuous variables between number of bleeding episode groups ( $\leq 11$ ,  $\geq 12$ ) and prophylaxis and on-demand groups, whereas Fisher exact tests were used to compare dichotomous variables between number of bleeding episode groups ( $\leq 11$ ,  $\geq 12$ ).

### RESULTS

Of the 181 eligible participants, 131 were enrolled; the median center recruitment rate was 77%. Children who did not participate in the study were similar to children who did with respect to age, type of treatment, race and ethnicity, and language spoken by their parents. Five participants were determined ineligible after entry either because their measured IQ was <70 ( $N = 4$ ), or because the level of fluency in English was not sufficient to complete the psychological tests ( $N = 1$ ). Therefore, data for 126 participants were available for analysis. Of the 126, 2 WISC-III scores and 3 WIAT scores were determined to be invalid by the examiners.

The mean age of the participants was 9.6 ( $\pm 1.9$ ) years. Clotting factor level was <1% in 86.5% of the children and between 1% and 2% in 13.5% of the

children. Parents of the children were primarily English speaking (92.8%). The racial and ethnic distribution was similar to that of the general US population of children with hemophilia<sup>19</sup>: 70.6% were white, 8.7% black, 11.9% Hispanic, 3.2% Asian, and 5.6% other races. Approximately 98% reported attending traditional school, and 2% were home schooled. Grades completed at the time of enrollment ranged from kindergarten through eighth grade, with approximately one half of the participants having completed less than the fourth grade.

Sixty-two percent ( $N = 78$ ) of the children were on prophylaxis at enrollment, and 9% ( $N = 11$ ) had previously been on prophylaxis but were currently on on-demand therapy. For those ever treated with prophylaxis, the duration of treatment ranged from 2.7 months to 7.7 years, with one half of the children treated with prophylaxis for >40% of their lifetime. Twenty-nine percent ( $N = 37$ ) had always been on on-demand therapy. The characteristics of participants categorized by treatment group are shown in Table 1. Children in both treatment groups were similar with respect to age, clotting factor level, parents' education, and IQ.

The median number of bleeding episodes experienced in the year before enrollment for the cohort as a whole was 12. The median number of bleeding episodes for children on prophylaxis at enrollment was significantly lower (6.0, range 0 to 58), compared with children on on-demand therapy (25.5, range 1 to 96;  $P < .001$ ). However, we observed that a substantial number of children on prophylaxis during the year before enrollment experienced a number of bleeding episodes greater than that of the cohort median. Of the 78 participants on prophylaxis at enrollment, 72 had been receiving prophylaxis for the entire year before entry, with 18 (25%) of the 72 reporting  $\geq 12$  bleeding episodes during that period. Sixty (83%) of the 72 children were on a regimen of prophylaxis that included  $\geq 3$  infusions per week. When children were categorized as above or below the median by the number of bleeding episodes that they had in the previous year ( $\leq 11$ ,  $\geq 12$ ), however, it was found that children in the high-bleeding category ( $N = 18$ ) were 3 times as likely (33.3% vs 11.1%) as those in the low-bleeding category ( $N = 54$ ) to be receiving  $\leq 2$  infusions per week ( $P = .061$ ). A review of the sites of bleeding reported for the 18 children

**TABLE 1.** Characteristics of Participants by Treatment Group

	Ever on Prophylaxis ( $N = 89$ )	Always on Demand ( $N = 37$ )
Mean age in years at enrollment (SD)	9.5 (1.8)	9.6 (2.0)
Mean age in years at onset of prophylaxis (SD)	5.5 (2.4)	NA
Mean duration of prophylaxis in years (SD)	3.7 (2.1)	NA
Mean percentage of lifetime on treatment (SD)*	40% (22%)	NA
Clotting factor level		
<1%	87.6%	83.8%
1%–2%	12.4%	16.2%
Mean years of parental education (SD)	13.7 (3.3)	13.1 (3.1)
Child's IQ (SD)	101.7 (13.9)	104.3 (14.4)

SD indicates standard deviation; NA, not applicable.

\* Percentage of lifetime on treatment = (years of treatment/age at enrollment)  $\times$  100.



revealed that 12 (66.6%) experienced  $\geq 25\%$  of their bleeding episodes in the same joint.

The prevalence of a previous diagnosis of psychological or developmental disorder reported by parents was generally similar in both bleeding episode groups. Learning disability or dyslexia was reported for 7.2% of the cohort, and developmental language delays were reported for approximately 9%. The reported rate of attention-deficit/hyperactivity disorder was 10.3% for the entire cohort and did not vary by category of bleeding episodes. Although parents were asked about the occurrence of a number of other conditions, including sleeping, eating, hearing, mood, anxiety, and motor skill disorders, these were reported with very low frequency or not at all in this cohort.

### Number of Bleeding Episodes and Achievement

The mean achievement scores were within the average range of academic performance: reading, 100.4 ( $\pm 15.0$ ); mathematics, 101.6 ( $\pm 15.0$ ); language, 108.1 ( $\pm 12.8$ ); writing, 95.4 ( $\pm 16.0$ ); and total achievement, 102.5 ( $\pm 14.2$ ). When children were categorized as above or below the median by the number of bleeding episodes they had in the previous year ( $\leq 11$ ,  $\geq 12$ ), those who had a low number of bleeding episodes had higher total achievement ( $P = .026$ ) and mathematics scores ( $P = .030$ ) than children in the higher bleeding episode category after adjusting for IQ and parents' education (Table 2). Most children in the low bleeding episode group (90.3%) were being treated with prophylaxis. Treatment with prophylaxis per se was not associated with better test scores in mathematics (102.5 vs 99.5,  $P = .138$ ), reading (101.0 vs 98.8,  $P = .331$ ), language (107.8 vs 109.0,  $P = .572$ ), writing (third grade and higher; 95.8 vs 94.3,  $P = .617$ ), or total achievement (102.9 vs 101.5,  $P = .442$ ). However, children who had been treated on a regimen of long-term prophylaxis ( $>40\%$  of their lifetime) and reported  $\leq 11$  bleeding episodes in the year before enrollment ( $N = 38$ ) had significantly higher scores in mathematics (105.2 vs 99.6,  $P = .009$ ), reading (104.0 vs 98.6,  $P = .018$ ), and total achievement (104.9 vs 100.6,  $P = .025$ ) than all other children reporting  $\geq 12$  bleeding episodes in the same time period ( $N = 63$ ).

### The Mechanism of the Association

Increased school absenteeism and hemophilia-related limitations in physical functioning among chil-

dren with greater frequency of bleeding episodes were proposed as the mechanisms for lower scores. In the current study, school absenteeism was lower, although not significant at the .05 level, for children in the low bleeding episode category ( $P = .054$ ; Table 3). In the total cohort, the number of bleeding episodes was positively correlated with school absenteeism (Spearman correlation = 0.23,  $P = .010$ ), and children with more school absences had lower scores in mathematics ( $P = .04$ ), reading ( $P = .006$ ), and total achievement ( $P = .002$ ) even after adjusting for the child's IQ and parents' education. Children with fewer bleeding episodes also had better PhS scores (see the Appendix for a description of the components of the PhS) than children in the high bleeding episode category (48.4 vs 41.3,  $P < .001$ ). The mean PhS for children in the low bleeding episode group (48.4) is similar to that of the general US population (50), but the mean PhS for children in the high bleeding episode group was almost a full standard deviation lower than the mean for the general US population. PhS scores were positively related to reading ( $P = .047$ ) and total achievement ( $P = .035$ ) scores after adjusting for IQ and parents' education.

### DISCUSSION

People with severe hemophilia have long been known to suffer morbidity from the musculoskeletal complications associated with recurrent bleeding events. These complications have led to investigation of replacement therapy methods to minimize or prevent these sequelae. Primary prophylaxis is commonly defined as infusion of clotting factor, usually beginning at a young age and at regularly scheduled intervals, which converts hemophiliacs from a state of severe clotting factor deficiency to a moderate or mildly deficient state. Although prophylaxis has known treatment benefits for severe hemophilia,<sup>20-23</sup> it is not universally practiced. Product availability is a major limiting issue in many countries. In countries where replacement products are available, prophylaxis may be limited by the following:

1. Cost
2. Patient acceptance and compliance
3. Difficulty in delivering frequent infusion therapy because of venous access problems

Research efforts continue to investigate whether other less intensive or demanding therapies have equally favorable musculoskeletal outcomes.<sup>1-4</sup>

Outcomes other than musculoskeletal sequelae should be considered in evaluating treatment regimens for young children with severe hemophilia. Higher school absenteeism rates compared with their

**TABLE 2.** Mean Achievement Scores\* by Number of Bleeding Episodes in the Year Before Enrollment

	Number of Bleeding Episodes in Previous Year		<i>P</i>
	$\leq 11$ ( <i>N</i> = 61)	$\geq 12$ ( <i>N</i> = 63)	
Mathematics	103.6	99.6	.030
Reading	102.2	98.6	.084
Language	107.6	108.6	.587
Writing (third grade and higher)	97.0	94.2	.326
Total	104.4	100.6	.026

\* Adjusted for child's IQ and parents' education.

**TABLE 3.** School Absenteeism by Number of Bleeding Episodes in the Year Before Enrollment

Number of bleeding episodes	Number of Days Absent		<i>P</i>
	Mean	Median	
$\leq 11$ ( <i>n</i> = 61)	7.6	5.0	.054
$\geq 12$ ( <i>n</i> = 64)	11.9	8.5	

nonaffected classmates<sup>6,9</sup> and lower academic performance relative to potential have also been documented.<sup>10</sup> The primary occupation of young children is preparation for and participation at school. Factors that interfere with completion of these important tasks can result in the inability of the child to fulfill his or her potential during school and later in life. Data from the current study show increased school absenteeism and a greater limitation in physical functioning, indicated by significantly lower PhS scores, for children in the high bleeding episode category. The type of information captured by the PhS includes limitations in physical activity, limitations in the kind or amount of schoolwork or social activities the child engages in, and presence of pain or discomfort.

A difference of approximately 4 points in total achievement was observed depending on whether participants experienced below or above the median number of bleeding episodes recorded for the study group as a whole, with mathematics and reading showing the strongest relationships. These differences in achievement are important for at least 2 reasons. They indicate a sizable shift in population mean scores for the children most affected by hemophilia, and the effects of hemophilia-related factors on academic achievement are thought to be cumulative over time. The children in this study were early in their school careers, so the differences observed may increase as the children advance through the middle and upper grades.

The current study has a number of important strengths. It reports the results of data collected from a population-based cohort with a high (77%) median center response rate. It is unique with respect to the depth and breadth of data collected about hemophilia, the social, demographic, academic, and behavioral characteristics of participants, school attendance, physical health, and measurement of potential and achievement. Although the sample size is modest ( $N = 126$ ), it is large compared with those of many other studies of children with hemophilia and was powered to detect a 5-point change in WIAT scores at 80% power. Central training and central coordination of study management, data collection, and analysis contributed to the standardization of study operations. Limitations of the study include its observational design; choice of treatment was at the discretion of the families, the children, and the physician; and compliance with therapy was not evaluated. It is possible that the observed relationship between lower number of bleeding episodes and higher academic achievement could result from some unknown factor or factors that lowered bleeding and increased scores but were not identified or measured in this study. Adjusting for 2 of the major predictors of academic achievement, the child's IQ and parents' education, minimized this risk.

Of interest and concern was the proportion (25%) of children who were reportedly being treated with prophylaxis during the year before enrollment but whose bleeding events were not optimally suppressed. This could result from an inadequate regimen such as insufficient dosing leading to lower than

adequate trough levels; poor compliance with the medical care plan; development of target joints with resultant synovitis before placement on a prophylactic regimen, with an increased tendency to hemorrhage even after prophylaxis was instituted; altered individual pharmacokinetics, resulting in more rapid than expected clearance or shortened half-life of the replacement product; and participation in activities with high risk of injury. Analysis revealed that of the 78 participants on reported prophylactic regimens at enrollment, 72 had been receiving prophylaxis for the entire year before entry, with 60 children receiving  $\geq 3$  infusions per week. A 3-times-weekly infusion schedule is commonly successful in suppressing bleeding episodes if dosing is appropriate and no target joints were present before initiation of prophylaxis. When children on prophylaxis were categorized by high ( $\geq 12$ ) versus low ( $\leq 11$ ) number of bleeding episodes in the year before enrollment, it was found that children in the high bleeding category were 3 times as likely as the low bleeding category to be receiving  $\leq 2$  infusions per week. This suggests an inadequate prophylactic regimen and hence inadequate suppression of bleeding episodes. In addition, a review of the bleeding sites for the 18 children on prophylaxis in the  $\geq 12$  bleeding episode group revealed that 66.6% experienced  $\geq 25\%$  of their bleeds in the same joint, data that are consistent with the presence of a target joint. Therefore, although many children were reported to be on a prophylactic regimen, an inadequate infusion regimen or previous presence of a target joint may affect the number of breakthrough episodes experienced. In the current study, children on long-term prophylaxis with successful bleeding control had higher scores in mathematics, reading, and total achievement. These data point strongly to the fact that patient and provider reports of prophylactic regimens of care must be scrutinized to ensure that bleeding is reduced.

Hemophilia A is a disorder affecting approximately 1 in 5000 male births. The observations made in this investigation, however important for this population, are not necessarily limited in their applicability to children with hemophilia and may be generalizable to some degree to other chronic illnesses and conditions that contribute to school absenteeism, interfere with physical function, and reduce a child's ability to participate in the normal endeavors of childhood. Testing this possibility by including a control group of children with another chronic disease, such as asthma, was beyond the scope of this investigation.

Each child should have the opportunity to achieve his or her potential. Control of a chronic disorder must include this important goal, as well as the more commonly identified medical outcomes. This study has identified an important association between the number of bleeding episodes experienced and academic achievement in a cohort of school-aged children with severe hemophilia. These data support the assertion that therapeutic care programs in this population must not be evaluated only in terms of financial cost to achieve adequate musculoskeletal outcomes. Also to be considered are the individual and

societal benefits of increased academic accomplishments if adequate suppression of hemorrhagic events can be attained.

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## APPENDIX

The following scales contribute the most to scoring of the physical summary measure, Child Health Questionnaire.<sup>18</sup>

### Physical Functioning Scale: 6 items that ask about limitations in the following:

Doing things that take a lot of energy, doing things that take some energy, getting around the neighborhood, walking 1 block, bending, lifting or stooping, eating, dressing, bathing, or going to the toilet.

### Role/Social Limitations due to Physical Health Scale: 2 items that ask about

Limitations in the KIND or AMOUNT of schoolwork or social activities due to physical problems.

### General Health Perceptions: 5 items that ask about

The child's health compared with other children, his or her resiliency, parental expectations about the child's future health, whether the parent worries about their child's health more than other parents, overall rating of health (from excellent to poor).

### Bodily Pain and Discomfort Scale: 2 items that ask

About the degree and frequency of bodily pain or discomfort. Landgraf, 1996. Reproduced with permission. All rights reserved.

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