

# Mild Hemophilia in a Competitive High School Soccer Player: A Case Report

Oluwakorede Omole, BA\*; Joan Reed, ATC\*; Amy L. Dunn, MD†; Courtney N. Gleason, MD\*‡

\*Emory University School of Medicine, Atlanta, GA; †Division of Pediatric Hematology, Oncology and Bone Marrow Transplant, Nationwide Children's Hospital, Columbus, OH; ‡Department of Orthopaedics, Emory University School of Medicine, Atlanta, GA

In this report, we discuss the case of a now 23-year-old athlete who was diagnosed with mild hemophilia, successfully played varsity soccer throughout high school, and continued to play intramural and club soccer while in college. A prophylactic protocol was developed by the athlete's hematologist to allow his safe participation in contact sports. Similar prophylactic protocols have been discussed by Maffet et al that successfully allowed an athlete to participate in high-level

basketball. However, significant barriers still exist for an athlete with hemophilia who wants to engage in contact sports. We discussed how athletes with adequate support networks can participate in contact sports. Decisions need to be made on a case-by-case basis and involve the athlete, family, team, and medical personnel.

**Key Words:** bleeding disorders, athletes, contact sports

Hemophilia is a genetic condition that is caused by a deficiency in coagulation factor VIII or IX, resulting in either hemophilia A or hemophilia B, respectively. Both of these otherwise clinically indistinguishable conditions are caused by X-linked recessive mutations. Hence, severe forms of hemophilia are predominantly male conditions affecting about 1 in 5000 live males with hemophilia A and 1 in 20 000 for hemophilia B.<sup>1</sup> People born female can also be affected by hemophilia, most commonly due to skewed lyonization of the X chromosome. These phenotypically affected females often fall into the mild hemophilia category with factor ranges of 6% to 40% and will often present with menorrhagia.<sup>2</sup> Hemophilia is characterized as mild, moderate, or severe based on the amount of clotting factor in the patient's blood (Table). The major manifestation of hemophilia is spontaneous or traumatic bleeding episodes. The frequency of the episodes usually correlates with disease severity and the effectiveness of prophylactic therapy. Spontaneous bleeds can occur into the joints and soft tissue but can also affect the mucosal surfaces and the central nervous system. People who have mild-to-moderate forms of hemophilia may not present with spontaneous bleeds but can bleed after an event, such as a sport injury or surgical procedure.<sup>3</sup>

Athletes with hemophilia have faced unique challenges in sports participation related to the risk of bleeding. Traditionally, these athletes have refrained from collision sports, which were once considered an "unnecessary risk" for this population.<sup>4</sup> As a result of decreased sports participation, individuals with hemophilia have typically been at increased risk for obesity, cardiovascular disease, diabetes, hypertension, hypercholesterolemia, and other long-term health complications resulting from limited physical activity and a stationary lifestyle.<sup>5–9</sup> Individuals who exercise regularly have decreased rates of depression and anxiety.<sup>10</sup> Patients with

hemophilia have shown increased levels of depression, with higher levels of depression and anxiety being reported in individuals with lower levels of perceived joint functionality.<sup>11</sup>

With the recognition of the benefits of regular physical activity and sports participation, recommendations regarding sports participation for athletes with hemophilia have begun to change where patients have access to high-quality treatments. The National Hemophilia Foundation was founded in 1948. In the most current recommendations from the National Hemophilia Foundation and Centers for Disease Control and Prevention, in the 2017 "Playing It Safe" guide, sporting activities are ranked in order of risk from 1 to 3. A ranking of 1 includes the safest of sports, such as swimming, and 3 includes the most dangerous sports, such as boxing.<sup>12</sup> Per these guidelines, individuals with hemophilia can safely participate in athletics if certain precautions are followed. Patients who wish to engage in sports should be evaluated by their hemophilia treatment center team and educated on recognizing and managing bleeds. Clear communication is necessary among the athlete, parents, hematologist, and athletic program so that a plan can be created to allow successful participation in sports.

The breadth of information in the literature regarding individuals with hemophilia successfully participating in athletics is still relatively limited. In this report, we present the case of an athlete diagnosed with mild hemophilia A who successfully engaged in varsity soccer throughout high school and remained athletic in college.

## DESCRIPTION OF CASE REPORT

### Patient

The athlete discussed in this paper is a now 23-year-old male who knew he had hemophilia throughout his life. His

**Table. Classification of Hemophilia Based on Severity**

| Severity of Hemophilia | Clotting Factor Level, % of Normal | Risk for Bleeding Episodes  |
|------------------------|------------------------------------|---|
| Mild                   | 6% to < 40%                        | Severe bleeding with major trauma or surgery; spontaneous bleeding is rare  |
| Moderate               | 1%–5%                              | Occasional spontaneous bleeding; prolonged bleeding with minor trauma or surgery                                  |
| Severe                 | < 1%                               | Spontaneous bleeding into joints or muscles, predominantly in the absence of an identifiable hemostatic challenge |

maternal great uncle was diagnosed with hemophilia; thus, shortly after he was born, his mother had him tested. His sister also has mild hemophilia. He has been involved in soccer from the age of 3. At the beginning of high school, he began to learn how to infuse factor on his own. In his sophomore year, after consulting with his hematologist and his parents, he started to play varsity soccer.

### Intervention

A prophylactic program was created by the athlete's hematologist. During the soccer season in high school, he self-administered prophylactic factor before every game to achieve a peak of 80% (2 to 3 times a week). He also carried 3 types of treatments with him. He used a standard intravenous factor VIII for prophylaxis, intranasal desmopressin (DDAVP), and aminocaproic acid for mucosal bleeds. He also followed an event-based prophylactic regimen for exertional activities. For major bleeds, he took 40 international units per kilogram of Advate, (Takeda Pharmaceuticals) and for minor bleeds, he took 1 spray per nostril of intranasal DDAVP, 0.15 mg, every 12 hours for up to 3 days. The patient restricted fluids to 48 ounces per day after use and would sip Gatorade to hydrate and reduce the likelihood of hyponatremia. At this time, he weighed 90.2 kilograms. If he sustained an injury during the season, he treated himself to a peak of 100% and administered prophylactic factor, 40 units per kilogram of Advate, before practice until the injury fully healed. However, when he was not injured, he typically went to practice without first taking prophylactic factor. He also wore a padded headband (Storelli Sports) to help avoid head injuries. He had a major injury in high school, in which he suffered a muscular injury to the lateral left leg and developed cramping pain rated 7/10 with activity during soccer practice after a holiday. No trauma, inciting incident, or swelling was noted. The athlete was examined by an orthopaedic surgeon; ultrasound imaging showed normal musculature and only minor vascular asymmetry. Vessel sclerosis was discussed but was ultimately decided against. Before the incident, he was not taking prophylactic factor because it occurred during practice. Rehabilitation from the injury took 3 months from the beginning of therapy until he returned to play. At the beginning of the treatment period, the patient administered 4000 units of Advate (40 units per kilogram), 2 times a week, and began physical therapy. The ankle was initially in a cast, but he was switched to a softer boot due to pain from the high pressure caused by bleeding.

Significant social factors contributed to how well this athlete was able to manage his condition. His mother had an uncle with hemophilia and understood the condition due to experiences with her family. His father was a physician and had played 4 years of National Collegiate athletic Association Division I soccer. He was able to help the athlete with medical

management of the condition and assist in teaching skills that would allow for safe participation in soccer, including avoiding headers and risky tackles.

### Comparative Outcome

In March of 2021, the patient was involved in an accident while biking. He sustained contusions to his thigh and shoulder. His shoulder healed well, but it took 20 days for his thigh to heal enough so that he could walk without pain. The athlete and his hematologist worked on a recovery plan together: maintaining peak goals of 100% for the first 2 weeks and self-administered factor to achieve peak levels of 50% for 1 month until the injuries were healed.

A similar case<sup>13</sup> has been reported of an athlete with moderate hemophilia participating in Division I basketball. The authors described the experience of a 20-year-old athlete who began participating in basketball without disclosing the diagnosis of hemophilia. He was injured during preseason practice and was found to have an existing diagnosis of moderate hemophilia. His athletic program was not able to allow continued participation because no safety protocols existed. However, with the guidance of the athlete's hematologist, a prophylactic protocol was developed that allowed the patient to participate on the basketball team for the next 2 years. A single dose of 3000 units of Kogenate FS (Bayer) at 30 units per kilogram was administered on Mondays, Wednesdays, and Fridays. An additional 4000 units at 40 units per kilogram was given 1 to 2 hours before the game. The protocol also required that the athlete travel with 6 doses of properly stored factor VIII for away games, all factor be infused in the presence of an athletic trainer or team physician, away games could be played only if within 75 miles (121 km) of a hemophilia treatment center, and no intramuscular injections be given.<sup>13</sup>

Similar protocols were developed for both athletes. It was important to achieve adequate control of the athlete's hemophilia. Notably, for the athlete in our case report, no special consideration was provided for distance to a hemophilia treatment center, he usually played in metropolitan areas, and he had extra doses of factor VIII when he traveled for games. Emergency treatment was also available for both athletes, and both athletes were very experienced in their respective sports.

### DISCUSSION

Historically, individuals with hemophilia have been discouraged from participating in collision sports due to the high risk of injury and bleeding. However, the abundance of benefits that can be gained from sports participation for young athletes means that safe participation should be encouraged. Zetterberg et al<sup>14</sup> showed that the benefits gained in muscle strength, endurance, and quality of life

outweighed the potential risks of participating in exercise if appropriate factor levels were maintained. Researchers<sup>15</sup> have determined that maintaining adequate factor levels further reduces the risk of bleeding. Physically, youth who participate in sports display increased strength, flexibility, and stability of their muscles; improved cardiovascular health; and lower rates of obesity. Involvement in sports has also been associated with more long-term career success.<sup>16</sup>

The case discussed here adds to the evidence that, with cooperation from parents, athletic trainers, physicians, coaches, administrators, and the athletes themselves, sports participation is safe and should be encouraged in athletes with hemophilia.<sup>17</sup>

The following items should also be considered when developing a protocol for athletes with hemophilia:

- (1) Cost: Without insurance, a single 1000-unit dose of Advate costs more than \$1000. The need for medication, specialized equipment and staff, adequate prophylaxis, and treatment may present significant barriers to participation.
- (2) Location: The medications required to treat hemophilia come from specialty infusion pharmacies, which can make them more challenging to obtain. Intranasal DDAVP (Stimate; CSL Behring LLC) for hemophilia is a special formulation that has been unavailable for the past year due to supply chain difficulties. Athletes living in areas with more or larger infusion centers may have better access to needed medications.
- (3) The individual athlete: The severity of the athlete's hemophilia is an important factor in the decision of whether to encourage participation in sports, particularly contact sports. Recommendations from the National Hemophilia Foundation discourage participation in contact sports for people with severe hemophilia.<sup>12</sup> The effect of strength training as a preventive measure to reduce the incidence of sports injuries is well documented.<sup>18</sup> The athlete's baseline strength and competency with strength training should be taken into account as part of the decision-making process. It is also vital that the athlete be included in all parts of the decision-making process. The patient's ability to adequately understand the risks of sport participation, proficiency with self-administration of factor, and expertise in the preferred sport must all be considered.

The data in this case report and the existing literature emphasize the important aspects to contemplate when assessing the level of intensity at which an athlete with hemophilia can engage. These reports provide the groundwork for the effective construction of similar protocols at other athletic programs and increase awareness of the need for a multidisciplinary team in the evaluation of athletes with hemophilia.<sup>19,20</sup> They also highlight the significant resources required for the successful implementation of these protocols. Sports should be accessible for athletes with hemophilia, and so further research and collaboration will promote the development of standardized guidelines to help relieve the administrative and cost burdens posed by these protocols.

### Clinical Bottom Line

The athlete discussed in this case report had a successful high school soccer career on a competitive varsity team

with only 1 major bleed associated with his underlying diagnosis of hemophilia. He followed an individualized treatment plan in which he self-administered factor VIII prophylaxis before all games and carried extra factor in the event of an injury or bleed during a game. We also emphasized the significant financial and individual factors that must be considered when an athlete with hemophilia wishes to participate in sports. With family support, athlete maturity, hematologist participation, a well-implemented treatment plan, and an educated sports medicine team, this patient's experience demonstrates that athletes with mild hemophilia can safely engage in soccer and other contact sports.

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Address correspondence to Oluwakorede Omole, BA, Emory University School of Medicine, Atlanta, GA 30322. Address email to oomole2@emory.edu.