

# Experiences of athletes with arrhythmogenic cardiac conditions in returning to play

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**BACKGROUND** Recommendations for return to play (RTP) for athletes with genetic (or congenital) heart diseases (GHD) predisposing to sudden cardiac death (SCD) have evolved from an initially paternalistic and conservative approach, to supporting a more flexible approach to decision-making. The experiences of athletes and their families during the RTP process are unknown.

**OBJECTIVE** To understand current RTP processes.

**METHODS** We administered a mixed-methods telephone interview combining quantitative and qualitative components to 30 athletes with a GHD who had RTP, and 23 parents. Participants were identified from the Yale ICD Sports registry and Mayo Clinic's Windland Smith Rice Genetic Heart Rhythm Clinic. Qualitative data were analyzed using a grounded theory approach to identify common themes.

**RESULTS** Most common diagnoses were long QT syndrome and hypertrophic cardiomyopathy and most common sports, soccer, basketball, and football. Twenty-three athletes encountered  $\geq 1$  perceived barrier(s) to RTP: 17 were restricted by their first

cardiologist; 6 were required to meet with school administrators, 4 signed waivers, and 3 hired lawyers. Common themes expressed by athletes and their parents were frustration with poor communication, perceived lack of physician knowledge of their diagnosis, and unilateral, paternalistic decision-making, as well as cynicism that physicians and schools were primarily concerned with liability. After RTP, 26 athletes had some form of emergency action plan, although responsibility was often left to the family.

**CONCLUSION** Many perceived barriers exist for athletes with GHD who wish to RTP after their diagnoses. Shared decision-making from the onset is critical for RTP.

**KEYWORDS** Shared decision-making; Athlete; Implantable cardioverter-defibrillator; Cardiomyopathy; Channelopathy; Sports

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## Introduction

Millions of young men and women participate in competitive high school or college sports annually, and physical and psychological benefits of sports are unquestioned. Young competitive athletes may be diagnosed with an arrhythmogenic genetic (or congenital) heart disease (GHD) through presentation with symptoms, preparticipation screening,<sup>1,2</sup> or cascade family screening.<sup>3,4</sup> When this occurs, decisions about returning to play (RTP) are difficult. Historically, competitive sports were restricted for athletes with congenital structural disease, cardiomyopathies such as hypertrophic

cardiomyopathy (HCM), channelopathies such as long QT syndrome (LQTS), and other disorders, a highly conservative approach based on caution in the absence or paucity of data.<sup>5–7</sup> However, sports participation carries numerous benefits to physical and emotional health, and restriction can decrease quality of life.<sup>8</sup> With the emergence of new data suggesting risk of sports may be lower than hypothesized for some cardiac conditions,<sup>9,10</sup> as well as recognition of clinical uncertainty as reflected in the use of class/level of evidence designations, the newer 2015 consensus recommendations from the American Heart Association now state that participation for many athletes “may be considered” based on patient- and sport-related factors.<sup>11–13</sup> These changes support more flexible decision-making for many conditions. Shared decision-making (SDM), in which

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## KEY FINDINGS

- Athletes face multiple barriers in returning to play after diagnosis of a potentially arrhythmogenic condition.
- Many athletes and their parents express frustration around poor communication, perceived lack of physician knowledge of their diagnosis, and unilateral, paternalistic decision-making, as well as cynicism that physicians and schools were primarily concerned with liability.
- Emergency action plans after return varied and were often left up to the athlete and family.

physicians aid patients in making decisions concordant with their values and preferences, now forms the foundation for decision-making throughout the medical community<sup>14</sup> and is now specifically recommended in the 2020 European Society of Cardiology guidelines on sports participation<sup>15</sup> for some cardiac conditions.

Despite initial restrictions, many athletes have returned to play.<sup>9,10</sup> In our previous partnering with patients and families to collect data on safety of sports for athletes with GHDs,<sup>9,10</sup> many anecdotally recounted a difficult and frustrating RTP process, some even changing academic institutions in order to return to the field. In order to better understand the experiences faced by athletes and their families in this process, we systematically surveyed athletes who had returned to competitive sports after the diagnosis of cardiovascular disease, as well as their parents.

We sought to understand the decision-making process encountered and how this process affects the athlete's experience and their emotional well-being. While the concept of incorporation of SDM into decisions around RTP is emerging,<sup>16-19</sup> to what extent this has entered practice is unknown. Also, little is known about the experiences of athletes with cardiovascular disease who do RTP—what safeguards are put into place, and how their GHD impacts their experience as an athlete and team member.

Thus, the goals of this mixed-methods survey, employing both quantitative and qualitative (open-ended) methods, were to understand the experiences of athletes in the process of RTP, as well their experiences after return. These data may guide improvements to these processes and thus enhance the well-being of athletes who wish to continue sports participation after a GHD diagnosis.

## Methods

Athletes with GHD who had continued to participate in sports at the high school or college varsity level after their diagnosis were identified either through the Yale ICD Sports Registry<sup>10</sup> or through chart review of the Mayo Clinic Windland Smith Rice Genetic Heart Rhythm Clinic. All were contacted through phone calls, letters, or e-mail and consent was obtained via phone (Yale ICD Sports Registry patients) and written consent (Mayo Clinic patients), as approved by each institution's

**Table 1** Demographic, clinical, and sport characteristics (N = 30 patients)

	N (%) or mean
Sex, female	15 (50)
Age at diagnosis (years)	12.4
Age at interview (years)	24.8
Diagnosis	
Long QT syndrome	13 (43)
Hypertrophic cardiomyopathy	5 (17)
Catecholaminergic polymorphic ventricular tachycardia	3 (10)
Congenital heart disease	3 (10)
Idiopathic ventricular fibrillation	3 (10)
Brugada syndrome	1 (3)
Arrhythmogenic right ventricular cardiomyopathy	1 (3)
Left ventricular noncompaction	1 (3)
Method of diagnosis	
Cardiac arrest	12 (40)
Syncope/presyncope	5 (17)
Other signs/symptoms	4 (13)
Family screening	6 (20)
Other screening	3 (10)
Treatment	
Beta blockers	25 (83)
Implantable cardioverter-defibrillator	21 (70)
Ablation	6 (20)
Left cardiac sympathetic denervation	4 (13)
Primary sport played	
Soccer	8 (27)
Basketball	6 (20)
Baseball/softball	5 (23)
Lacrosse	2 (7)
Tennis	2 (7)
Track	2 (7)
Martial arts	1 (3)
Rowing	1 (3)
Volleyball	1 (3)
Wrestling	1 (3)
Highest level of competition	
High school	13 (43)
College club	3 (10)
College varsity	11 (37)
Professional/semi-professional	3 (10)

Institutional Review Board (The Mayo Clinic Institutional Review Board and Yale Human Research Protection Program). Attempts were made to contact 34 athletes at Mayo; 16 were reached, and 13 signed consent. Among 36 Yale ICD Sports Registry athletes meeting the above criteria who had given permission to be contacted for future studies, 17 were reached; all verbally consented. Twenty-two parents (1 each of 22 athletes) also consented and were interviewed.

These 30 patients underwent a 30-minute mixed-methods quantitative and qualitative phone interview covering aspects of their cardiac disease, sports participation, and the process of RTP in sports. Experiences after return, including any emergency action plan (EAP) as well as impact on the team, were also queried. Demographic and clinic data were recorded during the interview. Surveys appear in the [Supplemental Appendix](#). Qualitative studies, including open-ended interview questions, are most useful in eliciting

patient experiences and perspectives, as well as understanding processes, particularly in areas without prior data to guide a quantitative survey.<sup>20</sup> Qualitative data were analyzed (KS, CG) using a grounded theory approach, implying the development of hypotheses based on analysis of the data collected, to identify common themes among participant responses and were applied uniformly across all participant transcripts.<sup>21,22</sup>

We developed a code structure, assigning labels to emerging themes, in stages and in accordance with the principles of grounded theory, using systematic, inductive procedures to generate insights that reflect the views expressed by participants. First, the 2-member research team independently coded the same 4 transcripts. We used the constant comparative method, going back and rereading and comparing transcripts as new concepts and insights emerged, to ensure that emergent themes were consistently classified, to expand on and refine existing codes, and to identify novel concepts. Second, the research team met regularly to achieve consensus and finalize a comprehensive code structure capturing all concepts derived from the data. We then systematically applied the final code structure to all transcripts.

## Results

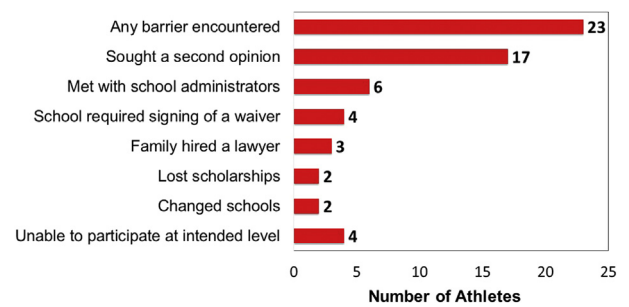
### Demographic, clinical, and sports characteristics

Demographic, clinical, and sports-related data for the 15 male and 15 female athletes are shown in [Table 1](#). The most prevalent diagnoses were LQTS (n = 13) and HCM (n = 5). Twelve athletes were diagnosed after a sudden cardiac arrest (SCA), 6 following an episode of syncope/presyncope, and the remainder were asymptomatic at time of diagnosis. Of these, 5 were diagnosed through family screening. Most athletes (n = 18) had at least 1 relative with the same diagnosis. Most athletes (n = 25) were on beta blockers, 21 had an implantable-cardioverter defibrillator (ICD; 20 transvenous, 1 with epicardial leads tunneled to abdominal generator), and 10 underwent either left cardiac sympathetic denervation or ablation. The most prevalent primary sports included soccer, basketball, and football. The highest level of sports participation included semi-professional (n = 3), college varsity (n = 11), college club (n = 3), and high school varsity (n = 13).

### Processes for return to play

Athletes saw a median of 2 and a maximum of 7 physicians in consultation regarding RTP after their diagnosis. The large majority (n = 23) of the athletes reported experiencing a complex and often disjointed process before RTP: 17 were disqualified from sport by their first cardiologist; 6 had to meet with school administrators after initial school refusal, 4 were asked to sign waivers, and 3 hired lawyers to contest the school's disqualification. These barriers led 2 athletes to change schools; 2 had scholarships revoked (these were all athletes with a history of cardiac arrest, and ICDs); and 2 were unable to participate at their intended level (eg, club instead of varsity) ([Figure 1](#)).

In qualitative analysis of open-ended questioning regarding processes into their RTP ([Supplemental](#)



**Figure 1** Perceived barriers to participation.

[Appendix](#)), the perceptions of athletes and parents, reported spontaneously in response to open-ended questions, included the following themes:

#### *Lack of appropriate expertise*

Athletes, and even more commonly their parents, expressed frustration with perceived lack of physician knowledge of their diagnosis, noted specifically by 7 interviewees:

*“The cardiologist was probably the most inept doctor I’ve ever met in my life and he said that it was syncope vasovagal”*

- Mother of high school tennis player

*“The beta blocker she was on had never been given to children and had not been used generally for 10 years....I think they were very behind in terms of information and knowledge”*

- Mother of a high school pole vaulter

Access to physicians with appropriate expertise was the most commonly noted specific area for improvement:

*“I feel like more doctors should know about it because that was one of the reasons they told me I couldn’t do anything anymore. She was like I have like no clue, no inside research about your condition, so she’s just kind of like you’re done. So if she would have known more, I think it would have turned out differently.”*

- High school male basketball player

*“If they would have actually gone through the proper research before I arrived because they knew, I mean they knew a year and a half before I even came there if they would have known and done research and talked to my cardiologist before I even got there, I think that would have made everything 150% better or just smarter; I think they would have been smarter about it”*

- College male baseball player

#### *Communication*

Perceived lack of adequate communication was also a common frustration, noted by 12 interviewees, and a noted area for improvement:

*“So once I left [the hospital] I was still under the impression that I had had a seizure. Like no one told me that this was like a heart thing and no one really explained that to my parents either”*

- High school female tennis player

*“And no one really took the time to explain and like, I don’t know I’m like a young kid, and I’m like, cool, something happened and I bounced back. Like no one took the time to explain the severity of sudden cardiac arrest.”*

- High school female tennis player

#### *Cynicism around concern for liability*

Next, many expressed cynicism that physicians and schools had more concerns for their own liability than for the athlete’s well-being.

*“Yeah, he basically just said, look, I need to cover my ass. I can’t have you die on the field and then ESPN comes and says Dr [X] let him play on the field and he died.”*

- College male baseball player

*“...the cardiologist.... And she just like came in and it felt like she was very much trying to like cover her own ass”*

- College female tennis player

*“As a doctor, maybe he was trying to prevent any risk for himself by saying yup, it’s okay, and then something happens.”*

- College male soccer player

*“So that’s what kind of started the fallout with that doctor. I’m sure that they were just wanting to cover their own butts at my kid’s expense.”*

- Mother of college female soccer player:

#### *Unilateral, paternalistic decision-making*

This was the most common theme expressed, with 19 athletes or parents expressing frustration with what felt like a unilateral decision-making process with no room for discussion.

*“We got to go with what our doctors say and our doctors say you’re not fit to play...., no, you’re not going to be able to play.”*

- College male baseball player

*“...the school was you know, they just clapped their hands and said this is over.”*

- Father of college male baseball player

*“He got a scholarship. They offered him a position, we get to [xx] University and he has to get his physical and the team doctor put the brakes on and said, we don’t think he can play ball...Nope that’s not how [this school] does things. Nope, that’s not how we do it here.”*

- Mother of college male baseball player

*“Well, he’s the team physician for all the sports and basically, he decided that it wasn’t going to happen on his watch that he was going to have a kid with this on the rowing team. So he made an arbitrary decision”*

- Mother of college female rower

#### *Emotional/mental health*

The emotional/mental health toll on the athlete was a theme described by both athletes and parents:

*“Yes, I mean she was at age 14 and she went through, I mean to be honest, like probably a depression and really angry stage and had to go to counseling because she was—you know age 14 is tough for a young girl and that’s all she knew”*

- Mother of softball player with LQTS

*“They made me stop playing all sports. I couldn’t do anything at PE. They really put me in a bubble, which sucked... No. I mean, yeah, it was upsetting. It sucks that I probably would have been still playing baseball if it wasn’t for it, but there’s nothing I can do about it.”*

- Baseball player with LQTS

*“the coach...decided that he was going to pay us and her back, but he really at that point in time began psychologically and emotionally just lambasting her—sitting her for games, not allowing her to play a certain point—I mean, it got to where it was cruel...So at that point, she’s devastated...Do not quit because now a person is trying to destroy you, because there’s a part of me thinking okay, be furious with me, but wouldn’t you look at her and say, what a warrior!...we still live in a constant rage of what the coach did in terms of when he fought her and tried to destroy her...he did leave her with some permanent emotional residue or fallout from that.”*

- Father of ice hockey player with LQTS

#### **Athlete-parent interactions**

Among the 22 athlete-parent dyads, 18 were concordant in feeling that they were “on the same page” regarding decision-making (specifically queried; survey in [Supplemental Appendix](#)) while in 3 dyads, both felt they were not on the same page. Some differences in themes were noted. No athletes had reservations regarding RTP,

while 6 parents had had second thoughts. Two athletes felt anger toward their parents regarding restriction from exercise, both with a history of SCA (and ICD). While both athletes and parents described the toll on the mental health of athlete, this theme appeared more frequently, and in more detail, in the parent interviews, as exemplified above.

## Experiences after return to play

### *Emergency action plan*

On RTP, 26 athletes had some form of an EAP. Twenty-five were required to have an automatic external defibrillator (AED) with them at practices and tournaments, 4 to wear protective gear over their ICD, and 2 to wear heart rate monitors. The decision to implement an EAP was made by the athlete's cardiologist in 9 cases, by the school or trainer in 4 cases, and in the remainder by the athlete and their families independently. For the implementation of these EAPs, in 10 cases the athletes, in 4 cases the parents, and in 7 cases (all involving athletes with ICDs) the school trainer or administration was primarily responsible for having an AED on hand. Only 1 EAP was activated when the patient's ICD fired during a game. No other cardiac event occurred in relation to sports participation.

### *Qualitative athlete experiences*

While all the athletes in this survey were ones who had eventually returned to play, many felt that the process had taken a toll on their sports participation. Themes described included lost fitness, physical effects of medications, missing out on important competitions, having to quit one of their sports, or having lost collegiate scholarships. Many felt that they received disparate treatments, with increased time on the bench, reduced physical contact from their teammates, and overall hesitation by coaches to allow participation. Twelve athletes felt that their diagnosis changed the team dynamic. Most (9) stated that their teammates became even more supportive after their initial experience, but 3 stated that teammates became more cautious around them, and/or questioned why the athlete was not participating similarly to the rest of the team.

After these initial experiences, 28 athletes continued to participate in athletics, with 10 competing at the collegiate or grad school level (on a club or varsity team), 12 participating in recreational athletics or intramural leagues post college, 4 competing at a semiprofessional or international level, and 2 involved in coaching.

## Discussion

In our survey of 30 athletes who had RTP, the majority of patients and their families encountered numerous perceived barriers, including the need to consult multiple physicians, requirements of signing waivers, the necessity of hiring a lawyer, inability to participate at their intended level of competition, or the need to change schools. The most severe barriers were described by those with a history of SCA, despite

receiving ICDs. Many patients and their families expressed frustration with perceived lack of physician knowledge of their diagnosis, poor communication, and unilateral and paternalistic decision-making. Cynicism that physician and school concerns of liability were prioritized over the athlete's well-being was expressed by most families. Ultimately, for most athletes this process took both an emotional and a practical toll on their sports participation. These themes were expressed spontaneously in an open-ended format, and it is possible that even more of the athletes may hold these views.

Prior to 2015, when many of the interviewed athletes were diagnosed and competing, the clinical and societal approach for sports participation for athletes with GHD was highly restrictive, as consensus recommendations limited nearly every form of competitive sports participation for virtually all heart conditions. When challenged, the courts upheld the right of an institution to follow consensus recommendations, as in the case of Knapp,<sup>23,24</sup> who struggled with physicians, athletic directors, and school officials for the right to participate in college basketball. However, the Knapp decision did not state that physicians and institutions must, or should, follow consensus recommendations, and practices among physicians, as well as academic institutions, around sports restrictions varied considerably.<sup>25</sup>

Restrictions on participation are not without repercussions. Sports restrictions owing to ICDs have significant emotional impact on patients and their parents.<sup>8</sup> Among patients with HCM, the majority who restricted their exercise reported a negative impact on their emotional well-being.<sup>26</sup> The current data demonstrate that even athletes who eventually are able to RTP experience enormous emotional difficulty owing to being temporarily sidelined, with long-term effects of loss of scholarships, switching sports, or switching schools.

Frustration with a unilateral, paternalistic decision-making process was the most common theme expressed. Many patients and their families felt that their opinions were not taken into account, and instead decisions were made unilaterally by their physician and/or the school administration or legal departments. The majority of the athletes in this study were diagnosed during a period in which the existing consensus recommendation was the 2005 Bethesda guidelines, which presented recommendations for RTP in a binary, yes/no format. The most recent consensus recommendations, published in 2015 by the American Heart Association, however, support more flexible policies on RTP and shift away from paternalism to a more patient-centered model. Rather than a binary format, the current statement incorporates the now-standard American College of Cardiology format of class of recommendation and level of evidence.

These newer recommendations point the way toward SDM between athletes and their physicians to discuss the risks and benefits of sports participation in an individualized fashion. In SDM, termed the "pinnacle of patient-centered care,"<sup>14</sup> all involved parties share ideas and information, discuss risks and benefits, and ultimately come to a decision together. Efforts to apply these concepts to participation in sports<sup>16-19</sup> are ongoing, but no standardization for this

process exists. Templates for these SDM conversations have been suggested, which include the importance of education including risks, determination of patient values, and doctor-patient interactions.<sup>27,28</sup> Details will vary; for example, for some conditions, sports may accelerate progression of cardiomyopathy as well as presenting risk of arrhythmia. Type of treatment, such as presence of an ICD, as well as type of sport, such as degree of aggressive contact, will also influence the discussion. To what extent the landscape is already changing is unknown. This study suggests there is much to accomplish in involving patients and their families in the SDM process.

For SDM to be effective, physicians need to hone their communication skills. A major theme expressed was frustration with inadequate communication. Effective doctor-patient communication is central to patient-centered care and promotes reassurance, reinforces patient self-confidence, and builds a stronger patient relationship.<sup>29</sup> Poor patient communication, on the other hand, undermines trust, reduces patient utilization of the healthcare system, and increases malpractice litigation.<sup>30</sup> Physicians with better communication skills provide greater patient satisfaction and understanding and improved adherence, and interventions to alter patient-practitioner communication skills have improved cardiology outcomes.<sup>31</sup> In addition to doctor-patient communication, communication between consultants and school physicians is also critical.

Many athletes and families expressed frustration with a perceived lack of familiarity of many physicians with their GHD diagnosis, which led to many seeing multiple physicians. These GHD conditions affecting young people, such as cardiomyopathies and channelopathies, are rare, and athletes with these conditions even rarer. Early referral to cardiologists with deep expertise in these conditions and in the care of athletes may be helpful, to bring appropriate knowledge to the SDM encounter and to streamline the process, as recommended by current guidelines.<sup>13,32</sup>

Many athletes and families expressed a perception that concern for liability drove physician and school actions. How SDM may impact liability is not described. The National Collegiate Athletic Association policy on medical care for college student athletes<sup>33</sup> describes the “unchallengeable, autonomous authority of primary athletics health-care providers to determine...return-to-play decisions” and this authority has been upheld by the courts in the landmark Knapp vs Northwestern case.<sup>24</sup> However, in that decision, the right of a school to restrict an athlete based on the judgment of the team physician was predicated on reasonable decision-making; one marker of a reasonable decision was use of published professional-society recommendations. As these statements no longer recommend blanket restriction, whether or when the Knapp decision will continue to support restriction has not been determined.

After these athletes returned to play, challenges remained. First, while many did have an EAP in place, in some situations the formulation of this plan was left up to the family, in others the MD, and in others the institution. Similarly, in

some cases, the institution took responsibility for using the AED if needed; in others, this was left to the family. This process, currently highly variable, should be standardized. Recent guidance from the National Collegiate Athletic Association in conjunction with the American College of Cardiology recommends ensuring the training of anticipated responders in cardiopulmonary resuscitation and AED use, ensuring easy access to defibrillation, and integrating onsite responder and AED programs with local emergency medical services.<sup>34</sup> These recommendations should be considered by all bodies organizing youth sports.

## Limitations

We only identified athletes who had overcome existent barriers and were able to RTP. We do not know how many athletes have been denied or chose not to return to playing sports. Understanding how this impacted their well-being is an important avenue of future research. Also, the sample size was not large, although thematic saturation was achieved, the appropriate sample-size determinant for qualitative studies.<sup>21,22</sup> While just 3 athletes declined to participate, a number were not reached; whether this was owing to no-longer-correct contact information or disinterest cannot be determined. Whether these athletes are representative of all athletes who RTP is unknown. First, many were seen at specialized centers for GHD (Mayo clinic) or sites participating in the ICD Sports Registry. However, half of ICD Sports Registry participants were self-enrolled<sup>10</sup> and may be more reflective of the wider community. Also, not all sports were represented. While close to half played either soccer or basketball, considered by the American Academy of Pediatrics to be “contact sports,”<sup>35</sup> none in this survey (and very few in the ICD Sports Registry,<sup>10</sup> from which many participants were drawn) played more aggressive contact sports such as football or ice hockey, and whether experiences would be different is not known. Only athletes and families were interviewed. Interactions between patient and physician are not always seen the same way by both sides. Understanding the perceptions of physicians involved in RTP decisions is an important avenue of future research. Future research should also address the perceptions of schools and sporting institutions, as well as their EAP policies. However, patient-centered care demands inquiry into and understanding of patients’ experiences. Delving further into what factors shape the values and influence the thinking of athletes and families, such as scholarships or future plans, or broader life-informing beliefs, may further enhance this process.

## Implications for the Future

This study highlights an RTP process that can be complex and disjointed, and points towards opportunities for improvement. First, involvement of the athletes and their families using established processes of SDM is critical, now supported by recent guidelines. This will require improved communication between athletes, their physicians, and their academic

institutions. Early referral to specialists may be helpful. These improvements in the RTP process may help diminish the emotional toll and striking cynicism expressed by so many of the parents and athletes.

Also, after the decision to RTP, greater organization and oversight is needed in the development of EAPs. Protocols around communication among team members when an athlete returns to play with a cardiovascular diagnosis may be helpful as well. What evaluation and protocols for conditioning should be in place as an athlete returns to play is an important avenue of further research.

## Conclusion

The process for athletes with a potentially arrhythmogenic GHD who wish to RTP after their diagnoses, and their families, is distressing, with many perceived barriers and poor communication. Lack of involvement of athletes and families in the decision-making process is not consistent with current thinking around SDM in medicine, and is critical for RTP for athletes with GHD. Challenges in the lack of physician familiarity and perceived concern by physician and school for liability has delayed athletes' participation. These data set the groundwork for future studies to investigate improving the process for future athletes.

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**Authorship:** All authors attest they meet the current ICMJE criteria for authorship.

**Patient Consent:** Consent was obtained via phone (Yale ICD Sports Registry patients) and written consent (Mayo Clinic patients), as approved by each institution's Institutional Review Board (The Mayo Clinic Institutional Review Board and Yale Human Research Protection Program).

**Ethics Statement:** The Mayo Clinic Institutional Review Board and the Yale Human Research Protection Program approved the study. The research reported in this study adhered to the guidelines outlined in the Declaration of Helsinki.

## Appendix

### Supplementary data

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.hroo.2022.01.009>.

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